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ABSTRACT

This report analyzes the problem families and others face in locating and arranging appropriate services for people with dementia and discusses federal policy options for the development of a system to resolve the problem. Chapter 1 provides an overview of the problem and discusses the factors that determine what kind of system is needed to link people with dementia to services. Chapter 2 focuses on the informational aspects of the process by which people with dementia and their caregivers are linked to services. Chapter 3 discusses the need for outreach and case management for those who need assistance that goes beyond public education and information and referral. Chapter 4 discusses certain concepts and distinctions that are important in thinking about how to determine people's decisionmaking capacity and how to make decisions on behalf of people who are not capable of making decisions themselves. Chapter 5 focuses on the potential role a federally mandated linking system might play with respect to the quality and appropriateness of services to which it connects people with dementia. Chapters 6 through 8 describe the Veterans Affairs health care and health-related services and various state linking programs and community service systems, and analyze 11 categories of agencies that Congress could designate as a basis of a national linking system for people with dementia. (LLL)

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Finding help for people with Alzheimer's and other dementias

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CONFUSED MINDS, BURDENED FAMILIES

Finding help for people with Alzheimer's and other dementias

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Foreword

Taking care of a person with Alzheimer's disease or another disease that causes dementia is a distressing process that may last for many years. For a variety of reasons discussed in this OTA report, families and others often have great difficulty locating and arranging the health care, long-term care, and other services they need to help them care for their relative or friend with dementia. People with dementia who live alone and have no family member, friend, or neighbor to help them are not able to locate or arrange services for themselves and often are not aware of their need for services. As a result, some people with dementia do not receive any services. Some receive inappropriate services, and some are connected—sooner or later—to an agency or individual that provides the kind of help they need.

Not all services that may be needed for a person with dementia are available. The lack of sufficient services for people with dementia is an important public policy issue that was discussed at length in OTA's 1987 report, *Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias*, and remains to be resolved. To plan realistically for the care of their relative or friend with dementia, however, families and others need to know not only what services are available but also what services are not available.

OTA estimates that there are now about 1.8 million people with *severe* dementia in the United States. The recently reported results of a study in East Boston suggest that there may be as many as 4 million people with Alzheimer's disease at all levels of severity. Due to the aging of the population, these numbers will increase dramatically in coming years.

This OTA report analyzes the problem of locating and arranging services for people with dementia, presents a framework for an effective system to connect them to appropriate services, and discusses congressional policy options for establishing such a system. One of the main policy issues is whether the system should serve people with dementia exclusively or serve people with other diseases and conditions as well. Some Alzheimer's advocates and others believe that only a system intended to serve people with dementia exclusively would be sufficiently responsive to their unique problems and needs, whereas others believe that a system intended to serve people with dementia and people with other diseases and conditions as well would be more effective than a dementia- specific system in connecting people with dementia to appropriate services.

In the course of this study, OTA has been impressed by the large number of agencies and individuals that are trying to provide appropriate services for people with dementia and to connect them to the kinds of services they need. To establish an effective system to connect people with dementia to services would require the coordination and consolidation of these agencies' and individuals' efforts and would undoubtedly engender some conflict and disagreement about which agency or individual should implement the system in a given State or community or at the national level. On the other hand, the lack of such a system means that the continuum of care these agencies and individuals are trying to create may not be accessible by the patients and families who need it most.

On behalf of OTA, I wish to thank the advisory panel, OTA's contractors, and the many other individuals who helped OTA in the preparation of this report. As with all OTA reports, the content of the report is the sole responsibility of OTA and may not reflect the views of those individuals.

John H Gibbons

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Chapter 1

Summary and Overview

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Chapter 1
Summary and Overview

INTRODUCTION

In 1987, OTA issued a comprehensive report on Alzheimer's disease and other diseases that cause dementia, *Losing a Million Minds: Confronting the Tragedy of Alzheimer's and Other Dementias* (831). That report described the devastating impact of dementia on the person and the equally tragic consequences for the person's family. It discussed the care needs of people with dementia and the complementary roles of families, community agencies, and other paid service providers in meeting those needs. The report described Federal policy options to increase services, educate and train service providers, improve quality of care, and provide adequate funding for services through public and private sources.

A survey of family caregivers of people with dementia, conducted for OTA in 1986, raised one issue not addressed in the 1987 report. The survey found that, in addition to many other problems, family caregivers have great difficulty locating services. Many caregivers said they did not know what services were available in their community. When asked what kind of help they needed to care for their relative with dementia, the caregivers identified the need for assistance in locating people or organizations that provide care as second most important, following only the need for a paid companion to give the caregiver a rest (926).

Many of the State task forces and committees that have studied the problem of Alzheimer's disease and other diseases that cause dementia have noted the difficulties people encounter in locating needed services (see reports from Arizona (37), California (99), Connecticut (142), Florida (215), Georgia (246), Illinois (351), Iowa (360), Kansas (396), Kentucky (408), Maryland (497), Massachusetts (500), Michigan (530), Minnesota (536). Missouri (543), Nebraska (592), New Jersey (599), New York (602), Ohio (621), Oklahoma (626), Texas (790), Virginia (870), and Wisconsin (920)). The Wisconsin Task Force on Alzheimer's Disease and Other Irreversible Dementias reported:

> Alzheimer's family members often tell distressing stories about not knowing where to go for help, going from one service provider to another in a vain search for assistance, and being misinformed about the availability of services or eligibility for programs (918).

Family caregivers told the task forces and committees in other States:

> I tried to ascertain just where and what I might do to get some help. My help came from a support group. Nobody else knew anything (599).
>
> After a 3-year search, I am just learning of the different resources that are available. Why didn't I know sooner (412)?
>
> We just scratched and dug on our own (531).
>
> Many of the services and resources are, indeed, available. They are not well publicized so people don't know where to go for help. As an educated person who is part of the health care system, I found it difficult to obtain help for my father. Someone older, more upset, or confused and not well versed in our system might have found it impossible (412).

An adult day care provider told the Maryland Task Force: "Families don't even know what to ask for and may go through a maze of blind alleys before help is obtained" (696). The Texas Alzheimer Task Force concluded that: "One of the greatest burdens of the family caregiver is the lack of knowledge of community resources and the ability to obtain these resources" (790).

This OTA report analyzes the problem families and others face in locating and arranging appropriate services for people with dementia and discusses Federal policy options for the development of a system to resolve the problem. This chapter provides an overview of the problem and discusses the factors that determine what kind of system is needed to link people with dementia to services, including the relevant characteristics of people with dementia, of their families and other informal caregivers (if they have any), and of the service environment. The chapter presents a framework, including the essential components and criteria, for an effective system to link people with dementia to services. It describes many of the public and private agencies, organizations, and individuals that currently help some people with dementia and their caregivers find services. Lastly, the chapter identifies and discusses Federal policy options with respect to the development of an effective system to link people with dementia to services. The policy options address questions such as whether the system should serve people with dementia exclusively or other people as well, whether the agencies or organizations that constitute the system should also be responsible for allocating services and funding for services, and whether those agencies or organizations should be designated by the Federal Government or by the States.

In the abstract, the development of an effective system to link people with dementia to services seems far removed from the terrible personal losses associated with dementia for patients and their families. The need for such a system comes alive, however, for people who try to find appropriate services for a relative, friend, or client with dementia and confront the existing lack of accurate information about services and about funding for services and the often bewildering array of public and private agencies, individuals, funding sources, eligibility criteria, rules, and regulations that constitute the service environment in many communities.

Although the need for an effective linking system is clear, establishing such a system will be difficult, in part because of "turf issues." Many public and private agencies, organizations, individual health care and social service professionals, service providers, and others currently link some people with dementia to services and consider this function as part of their role. Designating certain agencies, organizations, or professional or provider groups to constitute a system to link people with dementia to services will engender resentment and resistance from the agencies, organizations, and professional and provider groups that are not chosen. One alternative is to designate a consortium of agencies and organizations to constitute the linking system in each community, but the process of creating and maintaining an effective consortium is not without its own difficulties. Given these obstacles, some people might argue that it is best not to try to establish an effective linking system. On the other hand, without such a system, some, and probably many, people with dementia will not be connected to appropriate services, and families and other informal caregivers, who already must bear the physical and emotional demands of caregiving, will continue to experience the frustration of not being able to obtain accurate information and assistance in locating and arranging services.

Overview of the Problem

Diseases that cause dementia destroy a person's ability to understand events and people in his or her environment and to plan for and take care of himself or herself. Alzheimer's disease and many other diseases that cause dementia are progressive, so that over time the affected individual becomes less able to function independently and more dependent on others for care. Eventually, many people with dementia become so debilitated that they require total care, 24 hours a day, for the rest of their lives.

As a dementia patient's condition worsens, his or her family and friends are faced with severe emotional losses—loss of the person they knew and meaningful aspects of the relationship they had with that person. They are faced simultaneously with the person's need for supervision, physical care, and many other kinds of assistance to compensate for his or her lost abilities. Because people with dementia often live for many years after the onset of symptoms, the family's experience of emotional loss and the patient's need for care are frequently prolonged.

Photo credit: Suzie Fitzhugh

Alzheimer's disease and many other dementing diseases destroy a person's ability to plan for and take care of herself or himself. As a dementia patient's condition worsens, the person must depend increasingly on her or his family or friends for supervision, physical care, and many other kinds of assistance to compensate for her or his lost abilities.

People with dementia who have no family or friends face alone their loss of memory and other cognitive functions and their decreasing ability to care for themselves independently. Although they manage on their own for a while, eventually they also need 24-hour care and supervision.

Some diseases that cause dementia are reversible with available treatments, but most are not. A careful medical evaluation can identify reversible dementias and indicate appropriate treatment, but there is no known cure for Alzheimer's disease or many of the other diseases that cause dementia. OTA's 1987 report stressed the importance of biomedical research to find ways to prevent or cure those diseases. That report concluded that such solutions are not likely in the near future. Until effective methods of prevention or cure are discovered, ways must be found to take care of people who suffer from the diseases.

Formal services, including medical, nursing, and social services; adult day care; in-home, nursing home, and respite care; and legal and financial counseling, can lessen the physical and financial burden for families and others who are taking care of people with irreversible dementia.[1] Good formal services—those that are appropriate to the needs of the person and his or her caregivers—also may mitigate the potentially devastating emotional impact of dementia on the family, support the patient's remaining abilities, and perhaps lessen the patient's anxiety and suffering.

As awareness of Alzheimer's disease and other diseases that cause dementia has increased in the past few years, appropriate services have been developed in many communities. Such services are not available everywhere, however, and more services are needed in most communities. Where appropriate services are available, they are often expensive, especially when they are needed for prolonged periods. Public funding and private insurance coverage for them frequently are inadequate.

Even if appropriate services are available and affordable or reimbursable through public programs or private insurance, families and others still may not be able to find them. This problem is, in part, due to the complexity and fragmentation of services at the community level. In many communities, health care, long-term care, social, and other services for people with dementia (and for people with other chronic conditions) are provided by numerous public and private agencies and individuals. The services are not coordinated, and the providers have different rules about whom they serve and what they offer. Public funding is available for some services through Federal, State, or local programs, but each program has complex regulations about who is eligible, what services are covered, who provides them, for how long, and in which settings. Since there is seldom any information about the quality of services provided by different agencies and individuals, families and others often have no basis for selecting one over another. Many families and others suffer, as a result. According to the Alzheimer's Association:

> A recurring theme in the history of each family's problems is the difficulty experienced in finding both medical and social resources for the diagnosis, management, and, particularly, the care of the patient whose mind and body are failing (16).

Physicians, other health care and social service professionals, service providers, and others refer some patients and their families to services and sometimes arrange services for them. Many public and private agencies and organizations provide information and referrals and case management to help people find services. The assistance provided by those individuals, agencies, and organizations meets the needs of some people with dementia and their families, but other patients and families do not get any assistance in locating and arranging services. Some families contact one agency after another in a haphazard, lengthy search for needed services. That process adds to the frustration of families who are already coping with the emotional losses associated with dementia and with the patient's need for physical care and supervision. In the end, some patients do not receive any services, and some receive services that are not appropriate for their needs.

For families and other informal caregivers, the problem of locating and arranging services is only one of the difficult aspects of caring for a person with dementia. Likewise, from a public policy perspective, the problem of locating and arranging services is only one of the problems that restrict access to appropriate services for people with dementia. Four other problems that restrict access to appropriate services are:

- the lack of sufficient services,
- the lack of adequate funding for services,
- the lack of education and training for service providers, and
- the poor quality of some services.

---

[1] See table 1-2 later in this chapter for a list of the services that may be needed for people with dementia.

The focus in this report on the problem of locating and arranging services is not intended to detract from the importance of the other four problems, all of which were discussed at length in OTA's 1987 report (831). Ideally, through the combined efforts of public and private agencies and organizations, high quality services provided by well-trained individuals and adequate funding for services would be available to all people with dementia. That outcome is unlikely, however, at least in the near future.

Moreover, even if the other four problems were solved, the lack of effective methods of locating and arranging services would continue to restrict some people's access to appropriate services. Evidence discussed later in this report indicates that high quality services may not always be used, even when funding is available. Some patients and families do not know about the services. Other patients and families may need help in defining their needs, understanding how the available services can help, and arranging services. Even if high quality services were available everywhere, the problem of access would not necessarily be solved for those people.

In addition, an effective system to link people with dementia to services might help to resolve some of the other problems that restrict access. For example, precise information about service gaps often is a crucial factor in political and administrative decisions to establish or fund new services. If agencies that link people with dementia to services kept accurate records of the services that are needed but not available in their communities, that information might be used by policymakers to establish or fund new services.

A system to link people with dementia to services might also play a role in improving quality of care. OTA's research indicates that most agencies that help people find services do not have formal procedures to evaluate the quality of services to which they refer people, but some agencies do have such procedures (see ch. 5). It is reasonable to expect that if agencies gave their clients information about the quality of available services or referred them only to service providers who met certain standards, over time providers would try to meet the standards, and quality of care would improve generally. This report considers whether a linking system should concern itself with the quality of services to which it refers people, and if so, how.

The relationship between a linking system and funding for services is problematic. Many agencies that link people to services also help them find sources of funding for services. Public and private funding for services are not adequate, however. In 1988, 1989, and 1990, several bills were introduced in Congress to expand Federal funding for a variety of long-term care services. Provisions in most of the bills indicate that the agencies designated to administer the new benefits also would link people to services. Although the expanded funding for services proposed in the bills would benefit many people with dementia, it is not clear that the linking process proposed in the bills would meet their needs. In addition, some members of the advisory panel for this OTA study and other commentators are opposed to having the same agencies link people to services and administer or control funding for services. They fear that agencies that control funding for services may restrict, rather than facilitate, clients' access to needed services in order to limit the cost of the services to the agency. Both those concerns are discussed later in this chapter.

The issues of locating and arranging services, service availability, funding, provider education and training, and quality of care are interrelated. Some people might argue that one of the other issues is more important than locating and arranging services, and that limited public funds should be spent to create services, increase funding for services, support provider education and training, or improve quality rather than to develop an effective linking system. Clearly, however, better methods of linking people with dementia to services are necessary to ensure that they have access to appropriate care.

Congressional Interest

In recent years, with growing public awareness of and concern about Alzheimer's disease and other diseases that cause dementia, Congress responded first by funding biomedical research. Federal funding for biomedical research on Alzheimer's disease increased from less than $4 million in fiscal year 1976 to more than $140 million in fiscal year 1990. Federal funding for health services research also has increased, although much more slowly.

Legislation to improve access to services is just beginning. In 1987, the reauthorization of the Older Americans Act (Public Law 100-175) included new in-home services for frail, elderly people and specifically designated people with Alzheimer's disease and related disorders as eligible for the services. Each of the bills introduced in Congress in 1988, 1989, and 1990 to expand Federal funding for long-term care services defined eligibility for the services explicitly to include people with dementia. Most congressional attention has focused thus far on the issues of service availability and funding for services, however. Less attention has been paid to the question of how to link people with dementia to the services they need.

The topic of this report spans many Federal programs and crosses the jurisdictional lines of several congressional committees. The study was requested by the Senate Committee on Labor and Human Resources, Senator Charles E. Grassley, the House Committee on Energy and Commerce, and the House Select Committee on Aging. OTA received letters of support for the study from the Senate Special Committee on Aging; Senator Frank H. Murkowski, ranking minority member of the Senate Committee on Veterans' Affairs; the House Committee on Veterans' Affairs; and Congresswoman Olympia J. Snowe.

The primary concerns of the requesting committees and individual members of Congress were to improve access to appropriate services for people with dementia and to support family caregivers. The committees were particularly concerned about access problems in the Federal programs over which they have jurisdiction—i.e., Medicare, Medicaid, Older Americans Act programs, and programs of the U.S. Department of Veterans Affairs. The requestors were also concerned about the complexity and fragmentation of services and the competing claims of different agencies and professional groups that each of them should be the designated case manager. The requesting committees asked OTA to identify methods of locating and arranging services that are successful in some localities and might serve as models for other localities. The requestors agreed that a publicly funded system to link people with dementia to services should support the efforts of private groups, not supplant them, and several requestors stressed the need to evaluate the role of voluntary organizations in the service delivery system.

Locating Services for Mrs. D: A Case Example

The true story of one family's efforts to locate and arrange services for a relative with dementia (Mrs. D) is related in box 1-A. The process of finding services is different in every case: each person is different; some people with dementia do not have a family or other informal caregiver; families vary; and the number and type of service providers and the availability of public and private funding for services differ in every locality. Nevertheless, the experience of Mrs. D and her family contains some common themes and illustrates the impact on people of the fragmentation of services at the community level and the lack of an effective system. The story covers only a 1-month period. Many families of people with dementia experience similar problems for years.

Mrs. D has several advantages that many people with dementia do not have. She is not poor; she has a supportive family; and there are a substantial number of service providers and some public and private funding for services available to her. Despite those advantages, locating and arranging services for Mrs. D proved to be a difficult, frustrating process.

Box 1-A—Locating Services for Mrs. D

On February 29, 1988, Mrs. D, a 70-year-old widow, was hospitalized as a result of convulsions. She had been living alone in an apartment below the apartment of one of her three sons. The family knew that she was becoming confused, but when it turned out that the convulsions occurred because she mistakenly took too much of a prescribed diuretic medicine, they realized that she needed more supervision and assistance than she had been getting.

One son who lives 300 miles away took leave from work, and he and his two brothers and their wives who live in the area began to work together on a plan for Mrs. D. Their father had died the year before, after 8 years in a nursing home, and they were determined to arrange care for her at home.

On March 4th, while Mrs. D was still in the hospital, the hospital discharge planner gave the family a list of eight home care agencies in the area and suggested that they contact the local Medicaid office to determine whether Medicaid would pay for Mrs. D's home care.

One son called all the home care agencies. He was asked repeatedly whether he wanted a "homemaker" or a "home health aide." When he inquired about the difference, he was told that a homemaker was cheaper than a home health aide. One agency said that homemakers do not touch the patient, whereas home health aides do. Other agencies said this distinction was not true of their homemakers and home health aides, but they did not offer a better explanation of the difference between homemakers and home health aides.

The home care agencies quoted prices ranging from $7 to $12 an hour. Since Mrs. D needed supervision for as many as 16 hours a day, the cost could be $112 to $192 a day. Several agencies said they did not think Medicaid would pay for home care for her. Moreover, most of the agencies said that because of staff shortages, they could only "try to find someone." The family finally chose the nonprofit home care agency, partly because it had the lowest prices. Arrangements were made for a home visit.

One son contacted the Medicaid agency and was told that Medicaid might pay for a homemaker for up to 10 hours a day, 7 days a week. First, however, various procedures were needed to determine whether Mrs. D's physical condition and functioning were sufficiently impaired to meet Medicaid requirements for home care and whether she was financially eligible for Medicaid. Her income was slightly above the State Medicaid limit, but as her sons understood it, if she used part of her income to pay for some home care services, Medicaid might cover the rest.

On March 8th, the hospital called to say that Mrs. D was to be discharged that day. The family had expected she would be in the hospital at least 4 more days. One son called the doctor, who first said that Medicare would not pay for any more days in the hospital and that they had to take Mrs. D home immediately. The son argued that she had to stay at least 3 more days. Finally they agreed that she would be discharged in 2 days.

In the meantime, one son called the county Office on Aging, an agency that serves as the local area agency on aging (AAA) and as such is federally mandated to ensure the availability of information and referral for elderly people. He was asked whether Mrs. D needed "weatherization assistance" or food stamps. When the answer was no to both questions, he was told that the Office on Aging could not help.

The family continued to call every agency they heard about. They were repeatedly referred to the Office on Aging, and they called back once. That time, they got a completely different response, but again a response that was irrelevant to Mrs. D's situation.

Thus far, the family had not been given a diagnosis for Mrs. D's confusion. Her primary physician had said: "You know, it happens to all old people. She may improve." One son was convinced that she had an irreversible, dementing disease, but the other two sons accepted the doctor's hopeful suggestion that she might improve. As the difficulty of arranging home care and the potential cost of the services became clearer to the family, the three sons argued with each other about whether the services were really needed and, if so, for how long.

At a certain point, someone (the family can't remember who it was) suggested that they call the local senior center. The woman who answered the phone at the senior center said that the person they needed to talk to was out sick, and they would have to call back. She added, however, that her mother had Alzheimer's disease and that she knew of three adult day centers in the area that provided good care for people with dementia. She gave the family the name and telephone number of the one she thought was best.

(continued on next page)

Box 1-A—Locating Services for Mrs. D—(continued)

Mrs. D's family had not considered adult day care for her and did not know much about it, but one son called. He talked to the director of recreation and volunteer programs who gave the impression immediately that he understood the problem, knew about dementia, and might be able to help. The son arranged to visit the day center and called the hospital to have Mrs. D's records sent there so the center could decide whether to accept her.

On March 10th, Mrs. D came home even though the arrangements for her care had not been settled. Her sons continued calling service providers. They found it was difficult to supervise and care for her and at the same time make calls to arrange services. In the next 2 days, eight different people came out to evaluate Mrs. D. Some came from the home care agency, and some came from the Medicaid agency. The sons did not understand exactly who any of these people were or how they related to each other.

Mrs. D was very confused. She did not always recognize her son from out of town, who was staying with her. Frequently she got angry at him and at her daughter-in-law who lived in the apartment above her (whom she referred to as ''that government lady upstairs'') because they would not let her cook and do other things she wanted. She liked all the ''visitors'' who came to evaluate her. Once she was home, it was clear to everyone that she should not be left alone. Some family members began to wonder whether home care was even possible.

On March 12th, the son from out of town went home. The plan was that starting the next Monday, a home health aide paid by Medicaid would stay with Mrs. D seven days a week from 9:00 a.m. to 3:00 p.m. The family had hired another aide who would work from 3:00 to 9:00 p.m. and would be paid from Mrs. D's income. The son and daughter-in-law in the apartment upstairs would watch out for her at night. An application for adult day care was pending.

On March 14th, the first aide did not show up. It turned out she had quit the agency the previous Friday. The aide the family had hired privately came on time and worked out well. The next day an aide from the agency also came on time. The rest of that week went O.K. Mrs. D ''fired'' both aides frequently. The agency aide went to the daughter-in-law upstairs, who reassured her that Mrs. D needed help and told her that she should stay. The aide whom the family had hired turned out to be an easy going person with a lot of common sense; she didn't need to ask whether she should stay.

At the end of the week, the adult day center said that Mrs. D could come there, 5 days a week, starting in 10 days. The aide from the agency misunderstood, thought the plan was starting sooner, and did not show up for work the next Monday, leaving Mrs. D alone. In the meantime, one of Mrs. D's sons hired a college student to come in from 6:30 a.m. to 8:30 a.m., three mornings a week, because he was afraid that she was not safe alone then.

The adult day center has a grant for some of its costs, and clients are not required to pay a fee, but they are encouraged to ''contribute.'' Mrs. D's family was told that her ''contribution'' would be $15 a day.

The center could not provide transportation for Mrs. D. They have plans to purchase a bus in the future to pick up clients, but they do not expect to pick people up from as far away as Mrs. D's apartment. Medicaid can pay for transportation to the doctor and the hospital but not to the adult day center because, according to Medicaid regulations, it is a ''social day center;'' Medicaid could pay for transportation to a center that it defined as a ''medical day center.'' Mrs. D's family pointed out to the Medicaid case worker that Medicaid was paying the home care agency $11 an hour for an aide from 9:00 a.m. to 3:00 p.m. (although the aide got only $4.50) and that the adult day care would cost Medicaid nothing. The worker said that Medicaid's regulations on ''social day centers'' and ''medical day centers'' were firm, and that no exception could be made in this case.

Luckily, the aide that the family was paying privately said she would come every morning, get Mrs. D ready, take her to day care, and bring her home again in the afternoon. The family was paying her $7 an hour. Medicaid agreed to pay for another aide for 10 hours a day on weekends.

As of March 25th, the family was confident that the adult day center would provide good care. Since it is affiliated with a nursing home, they believed that she had ''one foot in the door there'' if she eventually needed nursing home care. They hoped the private aide they found would stick with the job. They were worried about Mrs. D at night, and for a few days they worried about what to do if she refused to go to the adult day center. Then they decided that she just didn't have that choice.

SOURCE: Office of Technology Assessment, 1990.

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FACTORS THAT DETERMINE THE KIND OF SYSTEM THAT IS NEEDED TO LINK PEOPLE WITH DEMENTIA TO SERVICES

In addressing the question of how to link people with dementia to appropriate services, OTA made no assumptions about what kind of system would be needed. By system, in this context, OTA means a group of interacting agencies and/or organizations that form a network that serves the common purpose of linking people with dementia to services. The system does not necessarily have to be federally administered, nor does it have to be implemented by a single category of agencies nationwide.

OTA's staff and the advisory panel for the study considered many possible systems, ranging from a relatively simple telephone information and referral system that would refer families and others to needed services to a comprehensive service system that would not only locate and arrange but also provide and pay for many of the services a person with dementia might need. The staff and advisory panel also considered whether the system—of whatever kind—should serve people with dementia exclusively or people with dementia and people with other diseases and conditions as well.

OTA concluded that three factors determine the kind of system that is needed to link people with dementia to services:

- the characteristics and service needs of people with dementia;
- the characteristics of their families or other informal caregivers (if they have any); and
- the characteristics of the service environment, including the number and type of agencies and individuals that provide services in a community and the sources of public and private funding for services.

The following discussion presents some general information about dementia and about each of the three factors that is relevant to determining what kind of system is needed to link people with dementia to services. Although the discussion identifies some common characteristics of patients, families, and service environments, it gives equal emphasis to their heterogeneity, since an effective system to link people with dementia to services must be responsive to their diverse needs and situations.

Characteristics and Care Needs of People With Dementia

On the basis of a 1985 review of epidemiologic studies, OTA estimates that there are now about 1.8 million Americans who have *severe* dementia: that is, they are so incapacitated that others must care for them continually (152). OTA estimates that an additional 1 million to 5 million Americans have *mild or moderate* dementia.

The prevalence of dementia increases with age. The 1985 review of epidemiologic studies found that the prevalence of *severe* dementia increases from less than 1 percent of people under age 65, to about 1 percent of those age 65 to 74, 7 percent of those age 75 to 84, and 25 percent of those over age 85 (152). Because of the aging of the U.S. population, the number of people with dementia will increase dramatically in coming decades.

Diseases That Cause Dementia

Dementia is a clinical syndrome characterized by the decline of mental functions in an alert individual. It can be caused by more than 70 diseases and conditions, including the following:

- progressive degenerative diseases, including those in which dementia is inevitable, such as Alzheimer's disease and Pick's disease, and those in which dementia may or may not occur, such as amyotrophic lateral sclerosis (ALS) and Parkinson's and Huntington's diseases;
- cardiovascular diseases that decrease blood supply to the brain: this can cause loss of brain tissue in the form of many small strokes (multi-infarct dementia) or one or more large strokes; bleeding into the brain,

usually related to hypertension, can also cause loss of brain tissue;
- severe depression;
- intoxication caused by prescription and nonprescription drugs and alcohol;
- infections that affect the brain, including Creutzfeldt-Jakob Disease and acquired immunodeficiency syndrome (AIDS);
- metabolic disorders;
- nutritional disorders;
- normal pressure hydrocephalus; and
- space-occupying lesions, such as brain tumors and subdural hematoma (847).

Alzheimer's disease is by far the most common cause of dementia. A study of noninstitutionalized individuals over age 65 in East Boston, Massachusetts, found that 91 percent of the individuals who had moderate or severe dementia had Alzheimer's disease, including 84 percent who had only Alzheimer's disease and 7 percent who had Alzheimer's disease plus another dementing illness (192).[2] Less than 5 percent had dementia caused by cardiovascular disease. The extent to which these findings from the East Boston study can be extrapolated to the population as a whole is unclear. Prior to the release of the findings from East Boston, other researchers had estimated that Alzheimer's disease accounted for only 50 to 60 percent of all cases of dementia, and that cardiovascular diseases accounted for 10 to 20 percent of all cases of dementia (399,794). Many researchers and clinicians have noted that Alzheimer's and other diseases that cause dementia coexist in some people (399,554,704,794).

Dementia in people with AIDS has received considerable attention from researchers, clinicians, and the media. Although prevalence estimates vary, researchers agree that most AIDS patients develop dementia at some time in the course of their illness (590,654). People with AIDS dementia face many of the same problems in locating appropriate services as people with other dementing diseases and some additional problems as well. This report does not address the difficult problems in locating services that confront AIDS patients specifically.

This report's main focus is on problems in locating and arranging services for people with Alzheimer's disease and other dementing diseases that primarily affect elderly people. Accurate identification of the disease that is causing dementia in an individual often is difficult, however. In Alzheimer's and some other dementing diseases, a diagnosis can only be confirmed with certainty by an autopsy after the patient's death (847). Diagnostic accuracy for Alzheimer's disease (confirmed by autopsy) approaches 90 percent in some specialized centers but is lower in other settings (226,400,831). Because of the lack of certainty about diagnosis in many cases, this report uses the generic phrase "people with dementia" except in describing research or programs that target people with a specific disease—usually Alzheimer's.

Cognitive and Self-Care Deficits

By definition, dementia involves some degree of memory loss. Other cognitive abilities frequently diminished or lost in dementia include intelligence, learning ability, problem solving, judgment, comprehension, attention, and orientation to time and place and to oneself. Language abilities, including the ability to express oneself meaningfully and to understand what others communicate, usually also are affected.

Researchers and clinicians have described a general progression of cognitive losses that typifies Alzheimer's disease and other primary degenerative dementias (339,511,710,711). It is important to note, however, that individuals with primary degenerative dementias vary in the rate and order in which cognitive losses occur (62,77). Individuals with multi-infarct and other dementing diseases also vary in the type, progression, and ultimate severity of their cognitive losses. Because of these variations and because, at any one time, individuals with dementia are at different points in their disease, people to be served by a linking system will differ greatly in the type and overall severity of their cognitive deficits.

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[2] The study in East Boston involved administering a brief memory test to 3,623 noninstitutionalized individuals over age 65 and then providing a comprehensive evaluation for 467 of those individuals, including 170 individuals who had performed well on the brief memory test, 101 individuals who had performed at an intermediate level on the test, and 196 individuals who had performed poorly on the test (192). Based on an analysis of the results of the comprehensive evaluations, the researchers concluded that at least 10.3 percent of all people over age 65 have Alzheimer's disease, including 3 percent of those age 65 to 74, 18.7 percent of those age 75 to 84, and 47.2 percent of those over age 85. Extrapolating to the population as a whole, these figures suggest that there are now about 4 million people with Alzheimer's disease in the United States. The prevalence of severe, moderate, and mild dementia due to Alzheimer's disease cannot be ascertained from the East Boston data.

People with dementia also differ in their self-care abilities. Variations in self-care abilities reflect, in part, the type and severity of individuals' cognitive deficits, their remaining cognitive abilities, and coexisting physical or emotional conditions. Cognitive deficits due to dementia often limit a person's ability to perform activities such as shopping, cleaning, cooking, using a telephone, and handling money, which are often referred to as "instrumental activities of daily living" (IADLs). As the person's cognitive deficits increase, the person also may become unable to independently perform personal care activities, such as bathing, dressing, or using the toilet, which are often called "activities of daily living" (ADLs). The person may forget how to perform any of the activities or even that they are necessary. Many dementing diseases cause neurological changes that create movement and gait disorders, swallowing disorders, speech impairments, and similar conditions that also limit a person's self-care abilities. Variations in self-care abilities also relate to environmental factors; for example, some people with dementia can perform certain activities in a familiar environment but not an unfamiliar one. Thus, the individuals to be served by a linking system will vary in the type and overall severity of their self-care deficits.

Self-care deficits generally increase as the severity of a person's cognitive deficits increase (217,293,787), but the correlation between the two is not exact. Some people with significant cognitive deficits are independent in self-care activities, and others with mild cognitive deficits have significant self-care deficits (760,895, 913).

Psychiatric and Behavioral Problems

Depression and other psychiatric and behavioral problems are common in people with dementia. Depression can cause dementia or co-exist with another dementing disorder. Differential diagnosis is difficult in such cases, but research indicates that one-fifth to one-third of people with Alzheimer's or another dementing disease have coexisting depression (695,704, 705).

Depression in people with dementia generally responds well to treatment (usually antidepressant medications) (444,512,682,705). If a person's cognitive deficit is due only to depression, his or her normal cognitive status may be restored with treatment. If the depression coexists with another dementing disorder, treatment usually does not improve the person's cognitive status. Often, however, it improves the person's mood and functioning—important considerations from the point of view of families and other caregivers (680,697).

Other psychiatric disorders that occur in some people with dementia are:

- suspiciousness and paranoia, identified in one-fourth to one-half of people with Alzheimer's disease (295,429,525,681,728, 787);
- visual and auditory hallucinations, found in at least one-fourth of people with Alzheimer's and other dementing diseases (242,525,681,728,787);
- withdrawal and reduced emotional responsiveness, found in three-quarters of the people with Alzheimer's disease in one study (729); and
- agitation and restlessness, found in 24 to 89 percent of people with dementia, depending on the study (242,479,729,787).

Behavioral problems that occur in some people with dementia are wandering, hitting, severe emotional outbursts, and disruptiveness at night (295,479,681). Not all people with dementia have behavioral problems, but when such problems occur, they often cause anxiety, embarrassment, fear, anger, and exhaustion for families and other caregivers. Even if the disease that causes a person's dementia cannot be cured, psychiatric disorders and behavioral problems associated with it usually can be alleviated with changes in the person's daily activities, modifications to his or her environment, training for caregivers in how to respond, medications, and in some cases, counseling and relaxation therapies for the patient.

Coexisting Medical Conditions

Many people with dementia have other medical conditions unrelated or only peripherally related to their dementing disease (71,211,479, 921). A random sample of people with dementia served by a community mental health center in Washington State, found, for example, that they had an average of more than three co-existing medical conditions. A third or more of the people had cardiac or vascular conditions, arthritis, and/or visual or hearing impairments (see table 1-1). Any coexisting medical condition can exacerbate a dementia patient's cognitive and self-care deficits and complicate his or her care. Conversely, treatment of the condition can maintain or restore the person's physical health and maximize his or her functioning (74,487,680,908,915).

Table 1-1—Coexisting Medical Conditions in 100 People With Dementia Served by the Community Mental Health Center in Spokane, Washington, 1988

Illness/Condition	Percent of people affected
Cardiac	40%
Vascular	31
Hypertension	34
Stroke	26
Arthritis	37
Vision impairment	50
Cataracts	30
Glaucoma	10
Hearing impairment	34
Speech impairment	19
Stomach ulcer	14
Chronic obstructive pulmonary disease	12
Cancer	11
Diabetes	11
Hernia	10
Parkinson's disease	9
Seizures	9
Osteoporosis/kyphosis	8
Urinary tract infection	8
Thyroid	5
Prostate	5
Diverticulitis	5
All others	12
None	7
Unknown	2

SOURCE: R. Raschko, director, Elderly Services, Spokane Community Mental Health Center, Spokane, WA, letter to the Office of Technology Assessment, U.S. Congress, Washington, DC, Mar. 8, 1988.

People With Dementia Who Live Alone

Most studies of people with dementia show that virtually all such people live either in the community with someone else or in a nursing home or other residential care facility (see, for example, Friss, 1989 (235); George, 1983 (242); Lusky et al., 1988 (479)). At the start of this assessment, OTA assumed that very few people with dementia were living alone and that those few probably were not severely cognitively impaired. OTA also assumed that a linking system would interact primarily with family members and other informal caregivers and should be designed to respond to their needs.

All those assumptions were wrong. The studies that show very small proportions of people with dementia living alone are based on interviews with family members and other informal caregivers. OTA's review of population-based studies and studies that focus on patients rather than caregivers shows that at least 20 percent of people with dementia live alone and that some of them are severely impaired. The Epidemiologic Catchment Area (ECA) Survey, a large-scale, population-based study conducted in five sites in the early 1980s, found that 24 percent of people with severe cognitive impairment were living alone.[3] The proportion varied considerably among sites, from 15 percent in New Haven, Connecticut to 44 percent in Durham, North Carolina (842). Twenty-one percent of people with dementia who were seen at the six California Alzheimer's Disease Diagnostic and Treatment Centers in 1985, 1986, and 1987 lived alone (225,227). Among people served by the National Channeling Demonstration Project, 24 percent of those with severe dementia and 33 percent of those with moderate dementia lived alone (149).

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[3] Severe cognitive impairment was defined in the survey as a score of 17 or less on the Mini-Mental State Examination (218). By that definition, the prevalence of severe cognitive impairment at the five sites averaged 1.3 percent in people over age 18 (range: 1.2 to 3.3 percent) (842).

Except for anecdotes, very little information is available about people with dementia who live alone. Data on 100 people with dementia who were receiving services from a community mental health center in Washington State in 1989, show that those who lived alone were somewhat less functionally impaired than those who lived with a caregiver: 80 percent of those who lived alone had limitations in ADLs, compared to 96 percent of those who lived with a caregiver. However, those who lived alone were older; their income was lower; and they had been receiving services from the community mental health center for a longer period (687). No data are available to compare the mental status of people in the two groups.

The large proportion of people with dementia who live alone is surprising. Some people with dementia who live alone have someone to help them—an important consideration with respect to both their service needs and the kind of system that is needed to link them to services. Among the 100 people with dementia who were receiving services from the community mental health center in Washington State, half of those who lived alone had an involved relative or friend (687). Extrapolating from those data and OTA's estimate that at least 20 percent of people with dementia live alone, one could hypothesize that at least 10 percent of all people with dementia live alone and have no one to help them. Some support for that hypothesis comes from data on people with dementia seen at the six California Alzheimer's Disease Diagnostic and Treatment Centers in 1987, 10 percent of whom had no relative or friend to help them (227). OTA is not aware of any other sources of data on this issue.

Service Needs of People With Dementia

Because of their cognitive and self-care deficits and psychiatric and behavioral problems (if any) people with dementia generally need supervision and assistance with many different kinds of activities. Families, friends, and others usually provide this care informally, but they cannot always provide all the assistance the person needs, and some people with dementia do not have anyone to care for them informally. People with dementia also need professional and specialized services that informal caregivers generally cannot provide.

Table 1-2 lists the many different kinds of services that may be needed for people with dementia and their families or other informal caregivers. Not all the services are needed for any one patient. Patients' and caregivers' needs change over time, however, and individual patients may need many of the services sometime in the course of their illness.

All the services listed in table 1-2 also are used for nondemented people with physical impairments. The cognitive deficits of people with dementia alter the nature of the services they need, however. Providing medical care, legal services, personal care, or other services for a demented person is quite different from providing the same services for a nondemented person, in part because the demented person often is unable to understand or cooperate with the provider. For that reason, even vision and dental care may be different for demented people. Various providers also differ in their knowledge about dementia and are more or less skilled in working with people with dementia.

Implications for an Effective System To Link People With Dementia to Services

Because of their diverse service needs, an effective system to link people with dementia to services must be able to refer them to many different kinds of health care, long-term care, social, and other services—ideally, to all the services listed in table 1-2—provided those services are available in the person's commu-

Table 1-2—Services That May Be Needed for People With Dementia and Their Families

Most of these services may be needed by and can be provided for patients who are living at home, in a nursing home, or in another residential care facility, such as a board and care facility, adult foster home, or sheltered housing.

- Diagnosis
- Acute medical care
- Ongoing medical supervision
- Treatment of coexisting medical conditions
- Medication and elimination of drugs that cause excess disability
- Multidimensional assessment
- Skilled nursing
- Physical therapy
- Occupational therapy
- Speech therapy
- Adult day care
- Respite care[a]
- Family/caregiver education and training
- Family/caregiver counseling
- Family support groups
- Patient counseling
- Legal services
- Financial/benefits counseling
- Mental health services
- Protective services
- Supervision
- Home health aide
- Homemaker
- Personal care
- Paid companion/sitter
- Shopping
- Home-delivered meals
- Chore services
- Telephone reassurance
- Personal emergency response system
- Recreation/exercise
- Transportation
- Escort service
- Special equipment (ramps, hospital bed, geri-chair, etc.)
- Vision care
- Audiology
- Dental care
- Nutrition counseling
- Hospice
- Autopsy

[a] Respite care includes any service intended to provide temporary relief for the primary caregiver. When used for that purpose, homemaker, paid companion/sitter, adult day care, temporary nursing home care, and other services included on the list constitute respite care.

SOURCE: Office of Technology Assessment, 1990.

nity. A linking system also should be able to refer people with dementia to service providers who are knowledgeable about dementia and skilled in working with people with dementia, again, provided there are such providers in the community. As noted earlier, many people with dementia have co-existing medical conditions unrelated or only peripherally related to their dementia. Since it is the whole person—not just his or her dementia—that is linked to services, the system should be able to refer patients to services or sources of information about services for co-existing medical conditions as well.

Certain services are needed early in the course of a patient's illness. An accurate diagnosis should be obtained as early as possible, both to identify reversible dementias and to let patients, families, and others know what is causing the person's cognitive and self-care deficits and psychiatric and behavioral problems, if any. Legal services also are needed early in the course of progressive dementing diseases, while patients still are able to make decisions about their property and future care and to execute legal documents (e.g., wills, trusts, durable powers of attorney, and living wills) that express their wishes on these matters. A linking system should be able to inform people with dementia, their families, and others about the importance of accurate diagnosis and early legal counseling. To do so, the system has to be in contact with them early in the course of the patient's disease.

Families and others often are not aware that the psychiatric and behavioral problems associated with dementia may be treatable, even if the underlying disease that causes the dementia cannot be cured. Likewise, they may not be aware of the impact of treatable coexisting medical conditions on the person's cognitive and self-care abilities. A linking system should take an active role in informing people that those problems and conditions may be treatable and should encourage them to seek appropriate treatment.

Dementia patients' characteristics affect not only the kinds of services to which a linking system must be able to refer them and the timing of the referrals but also many aspects of the linking process itself. Patients' cognitive deficits complicate the linking process, making it more difficult to connect demented than nondemented people to services. For example, people with dementia are far less likely than nondemented elderly and disabled people to refer themselves for services. People with dementia often are unaware of their own limitations and do not realize they need services. They are unlikely to be able to arrange or participate in arranging services for themselves, to remember service arrangements that have been made for them, or to remember and report problems with the services they receive (934).

People with dementia who live alone present a difficult challenge to anyone trying to locate and arrange services for them. Case managers interviewed for this OTA study said that such

Photo credit: Eastern Area Agency on Aging

A linking system must be available to people with dementia and their families early in the course of the patient's disease to inform them about the importance of obtaining an accurate diagnosis and early legal counseling.

people require more services and greater involvement of the case manager than people with dementia who live with a caregiver (see ch. 3). As noted above, some people with dementia who live alone have a relative or friend who helps them. People with dementia who live alone, and have no relative or friend to help them often are physically and emotionally isolated, fearful, and suspicious. They may be the most difficult patients to link to appropriate services. They also may be the most in need of services. To be effective, a linking system must have methods of reaching and working with them, as well as with patients who have an an informal caregiver to help them.

Many decisions are involved in the process of linking people with dementia to services, including decisions about what services are needed, who will provide them, who will pay for them, and, perhaps most importantly, whether the patient will be cared for at home or in a nursing home or other residential care facility. Because of their cognitive deficits, people with dementia may not be able to make those decisions for themselves, thus raising difficult questions about who should make the decisions and on what basis. Some people with dementia retain sufficient cognitive abilities to make decisions about services for themselves, but their decisionmaking capacity is likely to be uncertain and fluctuating (see ch. 4). Regardless of who ultimately makes the decisions, patients' cognitive deficits complicate decisionmaking in the linking process.

Lastly, the prevalence of co-existing medical conditions among people with dementia has implications for how they, their families, and others perceive their problem and service needs and how they are likely to enter the service system. For the purposes of this discussion, one could imagine a continuum of people with dementia that extends from a person who has dementia and no co-existing medical problems at one end to a person who has one or more serious medical problems and (often unnoticed) dementia at the other end.

The latter type—a person with serious medical problems and unnoticed dementia—is exemplified in the findings of two studies. One study concerned people who were hospitalized following a heart attack or heart surgery (53). Although all the subjects were considered free of any dementing illness, the researchers found that 40 percent had significant memory impairment and disorientation, and another 30 percent had milder cognitive deficits. Another study that concerned people hospitalized following hip fractures also found that 40 percent had significant cognitive deficits (67). These patients were in an acute medical care setting and had obvious medical care needs. If they continued to be cognitively impaired at the time of hospital discharge, appropriate planning for their post-hospital care would require taking their cognitive status into account. This would mean raising questions about whether the patients could comply with treatment recommendations (e.g., medication schedules and rehabilitation procedures) and whether the patients who had previously lived alone could safely continue to do so.

Patients such as those in the two studies just mentioned would benefit from a linking system that is skilled in working with people with dementia. On the other hand, since their cognitive deficits were not identified by hospital staff, it is unlikely these patients would have been referred to a linking system designated to serve people with dementia exclusively if such a system existed.

Hospitalized patients with unrecognized dementia represent one extreme on the continuum. OTA does not know how many such patients there are. In the middle of the continuum are people who have an identified dementing disease and co-existing medical conditions. From the perspective of this assessment, they would be categorized as people with dementia. In contrast, some families, physicians, and others would categorize them in terms of their other medical conditions and regard the dementia (if noted at all) as a complicating factor in the treatment of those conditions.

How families, physicians, and others perceive people with dementia determines to a great extent how they enter the service system. It also determines the type of agency or individual a patient or family will approach, be referred to, or accept assistance from in finding services. If a linking system is designated to serve people with dementia exclusively, it is unlikely to be used for those who have a dementing disease but are not perceived by their families, physicians, or others as "people with dementia."

Characteristics of Families and Other Informal Caregivers

Families, friends, neighbors, and others provide care informally for most people with dementia, and many families and other informal caregivers also link people with dementia to services (85,199,479,749). They may contact an information and referral or case management agency or contact service providers directly to arrange services. Other caregivers are unable to arrange services themselves. In either case, the characteristics of families and other informal caregivers affect the linking process, and understanding those characteristics is essential for determining what kind of system is needed to link people with dementia to services.

Photo credit: Cleveland Chapter of the Alzheimer's Association

Families and others who do not think of the person they are caring for as a "person with dementia" are unlikely to turn for help to a linking system that is designated to serve people with dementia exclusively.

Who Are the Informal Caregivers?

Informal caregivers of people with dementia are diverse. They vary with respect to their age, sex, and relationship to the patient; whether they live with the patient; their socioeconomic status; their educational, ethnic, and cultural background; their work and other caregiving responsibilities; and many less easily documented factors, such as the quality of their relationship with the patient and their attitudes about caregiving and the use of services.

No national data are available on the characteristics of informal care givers of people with dementia. One study in North Carolina of 501 caregivers of people with dementia found that 54 percent were spouses, 33 percent were adult children of the patient, 10 percent were siblings or other relatives, and 1 percent were friends (242). The caregivers ranged in age from 21 to 90, with an average age of 58. Seventy percent were women.

Some families care for more than one impaired person. A study of middle-aged women who were caring for their elderly mothers found that one-fourth also were assisting another elderly relative (83). The study described a couple in their early 30s, about to have their first child, who were caring for the wife's terminally ill mother and the confused grandmother for whom the mother had been caring.

Some people with dementia have several caregivers. Often, a primary caregiver provides most of the physical care and supervision, while other relatives and friends help out occasionally. These "secondary caregivers" frequently help to locate and arrange services (199,749). For that reason, patients who have a secondary caregiver may be more likely than other patients to receive services (483).

Although many informal caregivers are healthy and most are cognitively normal, some are physically frail, and some are almost as confused as the person they are assisting. One spouse or sibling who has been taking care of the other spouse or sibling for some time may become physically or cognitively impaired, or both. In that event, a linking system is confronted with the difficult task of arranging services for two impaired people living together, in effect, without a caregiver.

Employed Caregivers—At least one-third of caregivers of people with dementia are employed, full or part-time (242,448,655). Interviews with employed caregivers of demented and nondemented people and their employers indicate that caregiving and job responsibilities frequently conflict. Even if caregivers can arrange daytime care for the patient, they need to call service providers, take the patient to appointments, and go to government offices to apply for benefits during work hours. Worry about the patient also interferes with their productivity (198,233,443,603,797).

Employed caregivers of elderly people indicate that one of their greatest needs is for information about available services and sources of funding for services (443). A study that compared employed caregivers of cognitively impaired v. physically impaired elderly people found that the caregivers of the cognitively impaired people were more likely than the caregivers of the physically impaired people to express a need for information about services (740a). To be effective, a linking system must be accessible to employed caregivers and be responsive to their needs.

Long-Distance Caregivers—Many American families are geographically separated. The adult children or other relatives of a person with dementia may live far away but still try to function as long-distance caregivers. Little is known about long-distance caregivers of people with dementia. Commentaries on long-distance caregivers of elderly people in general indicate that they face extreme difficulties in trying to arrange and monitor services for a relative in another community (17,116,188). Such problems probably are more severe when the elderly person has dementia and cannot provide accurate information about his or her condition or monitor the services he or she receives. To be accessible to long-distance caregivers, a linking system must be identifiable in some uniform way nationally so that caregivers know who to contact for assistance.

Ethnic Minority Caregivers—Ethnic minority caregivers differ from each other in many ways, but there are some characteristics and attitudes that occur more frequently in ethnic minority groups than other societal groups and have implications for the kind of linking system that would meet their needs. The most obvious example is language differences. A linking system must be able to communicate with caregivers in a language they understand well because the details and decisions involved in locating and arranging services are both complex and emotionally loaded (866). More subtle differences are perceptions of dementia (e.g., whether it is seen as an illness, a part of normal aging, or "craziness") and attitudes about the use of services, both of which are influenced by each group's cultural heritage, beliefs, traditions, and customs. The special aspects of linking ethnic minority people with dementia and their caregivers to services are discussed later in this chapter.

Informal Caregivers of Nursing Home Residents With Dementia—Many informal caregivers continue to regard themselves as the primary caregiver after their relative or friend with dementia is admitted to a nursing home (198,244). Some visit daily and assist with personal care. Many continue to arrange medical and other services and to handle the person's financial affairs. Some try to arrange in-home services that would allow them to bring the person home. Thus, relatives and friends of nursing home residents with dementia are likely to continue to need and use a linking system.

Caregivers' Experience of Burden

Taking care of a person with cognitive and self-care deficits and psychiatric and behavioral problems can be exceedingly difficult. Having to watch the person's inevitable deterioration compounds the caregiver's distress. For these reasons, the family of a person with dementia is often the second victim of the disease.

Caregiver burden has been described in terms of:

- objective patient characteristics and behaviors that create demands on the caregiver;
- the caregiver's subjective experience of those demands; and
- the objective impact of caregiving on the physical and mental health, social participation, and financial status of the caregiver (932).

Patient characteristics and behaviors that are particularly burdensome for some caregivers include incontinence, severe functional impairments, hallucinations, suspiciousness, agitation, wandering, catastrophic emotional reactions, disruptiveness at night, behaviors dangerous to the patient or others, and the patient's need for constant supervision (125,295,681,938).

Not all caregivers experience those characteristics and behaviors as burdensome, however, and there is a surprising lack of correlation between patient characteristics and behaviors and the caregivers' subjective experience of them (244,643,668,938). Some caregivers' subjective experience of burden is less than might be expected given the objectively difficult situations they face (291,937). Moreover, many caregivers have positive feelings about caregiving and pride in their ability to manage difficult caregiving situations (125,242, 448,643).

To note those positive feelings and the lack of correlation between patient characteristics and behaviors and caregivers' subjective feelings of burden is not to minimize the problems faced by caregivers. In fact, informal caregivers of people with dementia experience more subjective feelings of burden and more negative consequences of caregiving (e.g., increased use of alcohol and psychotropic drugs, reduced immune function, and reduced participation in social activities than caregivers of other elderly people or other comparison groups) (71,242,291,296,411,415, 610,612,740a). The discussion here is intended only to highlight the complexity and diversity of caregivers' subjective experience of the demands of caregiving.

Anecdotal evidence suggests that the individuals who link people with dementia to services are not always aware of that complexity and diversity. For example, a physician, nurse, social worker, or other individual may observe a patient with severe cognitive and self-care deficits and frequent behavioral problems, assume the family is experiencing intolerable burden, and determine that nursing home placement is the only service option. The family, on the other hand, may feel that they are managing relatively well and may just want some respite care. When confronted with a recommendation for nursing home placement, the family may conclude that the individual making the recommendation does not understand, and the family may withdraw completely. As a result, the opportunity to link the patient and family to appropriate services is lost (see ch. 3).

Photo credit: Bill Adams

Taking care of a person with dementia can be exceedingly difficult. Nevertheless, many caregivers have positive feelings about caregiving and pride in their ability to manage difficult caregiving situations.

The opposite situation may also occur. A physician, nurse, social worker, or other individual may observe a patient with mild cognitive, self-care, and behavioral problems and assume wrongly that the family is not experiencing burden. If the patient and family are not linked to appropriate services, however, the patient may be at risk of inadequate care.

Many factors mediate between patient characteristics and behaviors that create demands on a caregiver and the caregiver's subjective experience of burden. Some of those factors are unchangeable (e.g., the age and sex of the caregiver), but other factors sometimes can be changed. One such factor is the caregiver's appraisal of the patient's characteristics and behaviors (297,487,533,938). Caregivers who view a patient's memory and behavioral problems as a direct consequence of a disease generally are less bothered by them than caregivers who view the same problems as in the patient's control, saying, for example: "If she paid attention, she wouldn't be so forgetful," or "He just does that to annoy me" (88). Education for caregivers about dementing diseases and their likely effects may lead to reappraisal of some problems and reduction in caregivers' experience of burden.

Coping mechanisms, such as seeking information, problem solving, and emphasizing positive feelings can also reduce subjective feelings of burden for some caregivers (88,295,610,938). Caregiver training and counseling can help some people increase their coping skills. Family support groups often give caregivers new ideas about how to solve or minimize problems and support to try those ideas (487,938).

Finally, social support provided by relatives, friends, church groups, and voluntary associations may reduce a primary caregiver's experience of burden (242,297,610,749,937). Family group meetings that involve other relatives and provide information about a patient's disease and its expected impact can sometimes reduce the primary caregiver's sense of isolation and increase the emotional support and practical assistance he or she receives (487,936).

Implications for an Effective System To Link People With Dementia to Services

To be effective, a linking system must be accessible to all kinds of informal caregivers and responsive to their diverse needs, including both the needs of caregivers who are as capable of locating and arranging services as any case manager and only need an accurate list of available services and the needs of caregivers who are completely incapable of locating and arranging services and are almost as impaired as the "patient." The system also must be responsive to differences among caregivers in their subjective experience of caregiving.

Lastly, a linking system must be aware of the potentially modifiable factors that affect caregivers' subjective experience of burden (i.e., their appraisal of patient characteristics and behavioral problems, their coping mechanisms, and available social supports). Interventions to modify those factors may reduce the caregivers' subjective experience of burden—a worthwhile end in itself—and change caregivers' views about the kinds of help they need to care for the patient—an important consideration for a system that is intended to link people with dementia to appropriate services. Some agencies that link people with dementia to services provide caregiver education, training, counseling, and support services that may modify those factors. Other agencies refer caregivers for such services. In either case, a linking system must recognize the importance of the services, or caregivers will not receive them.

Characteristics of the Service Environment

The kind of system that is needed to link people with dementia to services depends not only on the characteristics of patients and their informal caregivers but also on what services and sources of funding for services exist in a community. If sufficient services and funding and accurate information about both were available, the number of people who would need help to obtain services would be relatively small, although some, and perhaps many, people still would need help in defining the patient's needs, overcoming their own reluctance to accept help, and arranging services. At the other extreme, if there were no formal services or funding for services in a community, the functions of a linking system would be limited to helping people define their needs and mobilizing relatives, friends, and other informal resources to meet those needs. The reality in most communities is that there are some (although usually not enough) services and sources of funding for services, and accurate information about them often is not available. As a result, many patients and families need help not only to define their service needs but also to understand what services and funding are available and to locate and arrange available services and funding.

Types of Agencies and Individuals That May Provide Services for People With Dementia

In any given community, the kinds of services that may be needed for people with dementia may be provided by many different types of agencies and individuals. This is not to say that all the services are available, but that *if* they are available, they may be available from any of a great variety of agencies and individuals. Individual service providers include professionals in private practice (physicians, lawyers, nurses, social workers, psychologists, occupational therapists, physical therapists, speech therapists, audiologists, dentists, and dietitians), paraprofessionals, and nonprofessionals who provide homemaker, transportation, chore, and other services.

In some communities, the needed services are provided by public agencies. State departments of health, human resources, aging, social services, mental health, and public welfare or public assistance may provide some of the needed services through regional and local offices. Counties and other local governments provide some of the needed services through local health care, social service, and mental health agencies. Some local governments have community service councils, health coordinating councils, and community action programs that provide some of the services.

The U.S. Department of Veterans Affairs (VA) provides some of the services for eligible veterans, primarily through its 172 medical centers (see ch. 6). The U.S. Department of Defense provides some of the services for eligible military personnel and their dependents in military hospitals and clinics. Hospitals and clinics of the Public Health Service and the Indian Health Service also provide some of the services for eligible people.

Area agencies on aging (AAAs), community mental health agencies, community health agencies, adult day centers, home health agencies, homemaker, chore, respite, and transportation service agencies, and senior centers provide some of the services in some communities. Voluntary associations, such as the Alzheimer's, Parkinson's, and Huntington's disease associations, also provide some of the services, often through their State and local chapters.

Some hospitals and nursing homes provide some of the needed services on an outpatient basis, in addition to their traditional inpatient and residential care services. Private social service, nursing, family service, and senior service agencies provide some of the services in some communities. Other potential providers include churches, community ministries, the Salvation Army, YMCA, YWCA, United Way, and other service and philanthropic groups.

Not all those agencies exist in every community. If they do, though, they may provide services needed by people with dementia. Given the diverse needs of such people, many of the agencies are possible sources of assistance.

Factors That Limit the Availability of Services

Because there are many potential service providers does not mean that enough services are available or that a patient's needs can be met. As discussed in chapter 2, many details about an agency's services determine whether the services are really available to a particular patient and whether they meet his or her needs. These details include the agency's general eligibility criteria and any additional eligibility criteria for a specific service, the exact nature of the service, when and where it is provided and for how long, what it costs, and whether there is any source of funding for it other than client fees. These kinds of details often reflect regulations and requirements associated with the agency's funding source (e.g., Medicare, Medicaid, State programs). They may also reflect State or local government licensing or certification requirements; the agency's mission, objectives, and history; and the training and preferences of its staff (391,481,641,821,831).

The details of each agency's services change from time to time, especially in response to changes in regulations and requirements associated with its funding sources (641,821,922). Federal, State, and local governments and private associations and foundations initiate new services and terminate others. Publicly and privately funded research and demonstration projects that provide services also begin and end. Some of the changes are small, but their cumulative impact is to create a constantly changing service environment.

The number and type of agencies and individual providers vary in rural and suburban or urban areas. Some areas are "service rich," and others are "service poor." Rural areas are likely to be service poor. Some rural counties have no hospital, and a few have no physician. Many lack mental health professionals and other service providers. Because of low population density, residents of rural areas often have to travel a long distance to obtain services, and in some areas, there are not enough people with similar problems to justify specialized services (55,58,771,912).

Linking people with dementia to appropriate services in areas that have very few services is difficult. On the other hand, the more services there are in a community, the greater the complexity of the service environment. At one extreme, United Seniors Consumer Cooperative, a private consumer health care cooperative in Washington, DC, identified 130 public and private agencies that offer transportation services for elderly people in the Washington area (800). Obtaining enough information about those agencies to select an appropriate provider is difficult.

Sources of Public and Private Funding for Services

Services for people with dementia may be paid for by the individual, his or her family, public programs, or private, third-party sources. Since people with dementia often need services for years, they are likely to need public or private third-party funding in addition to their own resources. There are many potential sources of such funding. At least 80 Federal programs pay for services that may be needed for people with dementia or provide funds so people can purchase the services (828). Many State and local government programs, private agencies, and voluntary and charitable organizations also pay for services or give people funds to purchase them. Publicly and privately funded research and demonstration projects pay for services in some communities. Lastly, some people have private insurance that covers some services.

Factors That Limit the Availability of Funding for Services

The existence of many potential sources of funding for services does not mean that adequate funding is available. Each source has rules that limit the availability of funding by restricting who is eligible and what services are covered. Eligibility may be restricted on the basis of a person's age, income, assets, diagnosis, physical or mental condition, residence, family composition, and other factors. Coverage may be restricted by rules about the type of service that can be paid for; the profession, training, and/or licensure of a person who can be reimbursed for providing the service; the setting in which it can be provided; and its duration and frequency (124,391,641,831). The rules in each of these areas are interrelated, so that a particular service is paid for only if it is provided to a patient with a certain diagnosis or condition, by a certain provider, in a certain setting, for a given time period. To further complicate this already confusing situation, the eligibility and coverage regulations of funding sources change from time to time.

It is often unclear whether a person with dementia fits within the eligibility requirements for some funding sources, particularly Medicare and, to a lesser degree, Medicaid, that base eligibility on a person's physical condition and physical care needs. People with dementia frequently are determined to be ineligible for funding for services through these programs (124,186,479,831). On the other hand, some people with dementia receive services paid for by the programs. This may occur because of real differences in the physical condition and care needs of different patients, differences in the way a patient's condition and care needs are described on an application or billing form, or different interpretations of a program's regulations by its administrators.

Turf Issues Among Agencies and Individuals That Provide Services for People With Dementia

Turf issues are prevalent among the agencies and individuals that provide services for people with dementia. Simply stated, turf issues arise when one agency, type of agency, or type of professional or nonprofessional service provider regards the care of people with dementia as its turf and believes that it, rather than another agency, type of agency, or service provider, offers the "right" services for such people. Turf issues arise at the national, State, and local level and add to the complexity and fragmentation of the service environment.

Turf issues in the care of people with dementia arise between mental health and aging services agencies; health care and social service agencies; agencies that serve only people with dementia and agencies that serve elderly or disabled people in general; neurologists and psychiatrists; social workers and nurses, hospital-based home health care agencies, free-standing home health care agencies, and independent home care workers; for-profit and nonprofit agencies; and myriad other combinations of agencies and professional, paraprofessional, and nonprofessional service providers.

Sometimes, turf issues reflect self-serving competitions between agencies and individual providers for the public and private funds that pay for services and the jobs required to provide the services. Often, however, turf issues reflect sincere differences of opinion about which agencies and individuals provide the "right" services for the clients. Many of the agencies and individuals that provide services for people with dementia now have served the same kinds of clients for years, although not necessarily identifying them as people with dementia. As attention to Alzheimer's disease and other diseases that cause dementia has increased recently, those agencies and individuals claim—often legitimately—special expertise and skill in the care of people with dementia and regard the care of such people as their turf.

Sometimes, there is no explicit competition or difference of opinion about which agency or individual provider offers the "right" services for people with dementia. Instead, each agency, type of agency, or type of individual provider regards the care of people with dementia as its turf and is simply unaware of others who serve the same kinds of clients.

Services for people with dementia generally are provided in one of several broad systems of agencies and providers—i.e., the medical or physical care system, the mental health system, the social service system, the public health system, the public assistance system, and the aging services system. These systems are delineated by the Federal programs that fund them, the education and training of people who work in them, and historical divisions among State and local government agencies that administer the services they provide. Although not rigidly differentiated, the systems generally are not integrated with each other. Service providers in one system may not be aware of services in other systems. Moreover, agencies and individual providers in the same system tend to have a common perspective on dementia and the "right" services for people with dementia. Thus, they may have greater understanding of and confidence in services provided by other agencies and individuals in the same system than those in other systems. For all these reasons, referrals are more likely to occur within a system than from one system to another. For example, agencies in the aging services system may not refer clients to services provided by the mental health system, and vice versa.

The Complexity of the Service Environment for People With Dementia

The large number of agencies and individuals that may provide services for people with dementia, the large number of potential sources of funding for services, and the complicated and changing rules that limit the availability of both services and funding create an extremely complex service environment in many communities. Some communities have fewer agencies and individual service providers than others, but the rules that limit the availability of services and funding for services remain.

The complexity of services at the community level has been cited so frequently in discussions about health care, long-term care and social services for elderly and disabled people that it has become a cliche. Nevertheless, in the course of this study, OTA's staff was repeatedly amazed by that complexity. As one learns more about services and funding for services in a certain community, the service environment appears more, not less, complex. It is clear that there are some services and sources of funding for services in virtually every community but generally unclear whether those services and sources of funding are really available to people with dementia and what proportion of such people they serve.

Two factors make the service environment especially complex for people with dementia—even more complex than it is for elderly and disabled people in general. First, the service needs of people with dementia cross the boundaries of the broad systems of agencies and individual providers cited earlier to a greater degree than the service needs of most nondemented people. Second, in many communities, there are new services for people with dementia that are not well known and may serve very few patients but often provide good care to those they serve. One commentator describes the array of small, new services for people with dementia as a "cottage industry" (698).

Implications for an Effective System To Link People With Dementia to Services

The complexity of the service environment in many communities makes it clear why families and others have difficulty obtaining accurate information about services and funding for services. It also makes clear the need in all communities for an accurate, up-to-date list of available services and sources of funding for services. OTA does not have comprehensive data on how many communities have such a list, but evidence from various sources suggests that many communities do not (see ch. 2). Because of the large number of potential service providers and funding sources and the changing rules that affect their availability, maintaining an accurate list of services and sources of funding for services for people with dementia is difficult. Yet, such a list is essential for linking them to appropriate services.

At the start of this assessment, OTA's staff thought that the biggest problem families and others face in trying to obtain accurate information about services and funding for services is lack of information. In the course of the assessment, it became clear that wrong and partial information are at least as big a problem. For example, people who contact an agency or individual for information may be told that there are no services when, in fact, there are services, or vice versa. Likewise, they may be told that there is a service, e.g., an adult day-care center, 30 miles away when there is another center much closer. Given the complexity of the service environment and the lack of an accurate list of services and sources of funding for services in many communities, it is easy to understand why families and others receive wrong information or only partial information about services and sources of funding.

Having an accurate list of services would not change the complexity of the service environment at the community level or make up for the lack of sufficient services. It would improve access, however, and, by letting people know what services exist, it would allow for more appropriate use. Likewise, having accurate information about funding sources would not change the complexity and fragmentation of public and private programs that pay for services or make more funding available. It would increase the likelihood that people would receive benefits for which they are eligible.

It is important to note that families and others need to know not only what services and funding for services are available, but also what services and funding are not available. They need both types of information in order to plan realistically and to make informed decisions about the care of their relative or friend with dementia.

REASONS WHY PEOPLE WITH DEMENTIA AND THEIR CAREGIVERS MAY NOT USE SERVICES

No national data are available on the percentage of people with dementia who use paid services. The findings of 11 small-scale studies reviewed in chapter 3 indicate that only about one-quarter to one-half of all people with dementia who live in the community use any paid services other than physicians' services (71,88,117,223,227,242,291,411,479,448,774, 926). Among those people with dementia who do use paid services, many use very few services, use them infrequently, and/or use them very late in the course of their illness. The findings of two of the studies suggest that, on average, people with dementia use fewer paid services than people with physical impairments (71,255).

There are many reasons why people with dementia and their caregivers may not use services. Lack of knowledge about services is one reason—and, in the view of family caregivers and service providers in Cuyahoga County, Ohio, who were interviewed for this OTA study, it is the most important reason. Three- quarters of the caregivers and service providers who were interviewed said that people's lack of knowledge about services is usually a reason people do not use services (186).[4]

Knowledge about services has two components:

- general awareness of services, referred to in this report as *service consciousness*, and
- knowledge about a specific service, including who provides it in a community, referred to in this report as *service knowledge* (431).

Interviews with family caregivers of people with dementia in Cuyahoga County, Ohio, found that, depending on the specific service in question, up to 92 percent of the caregivers lacked service consciousness—that is, they had never heard of the service. Again, depending on the service, up to 96 percent of the caregivers lacked service knowledge—that is, they could not identify a specific provider in the community (186) (see ch. 2).

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[4] The results of the study conducted for OTA in Cuyahoga County are discussed in chs. 2 and 3. A full report on the study can be obtained from the National Technical Information Service in Springfield, VA (see app. A).

Other barriers to the use of available services are the cost of the services and the inability of patients and caregivers to arrange the services. Three-quarters of the caregivers interviewed in Cuyahoga County, Ohio, said that inability to pay for services was a reason why they did not use services. Half the caregivers said that not knowing how to arrange services was a reason they did not use them (186).

Often, it is fear of future costs rather than the current cost of services that stops caregivers from using services. Some caregivers who participated in Duke University's Respite Care Demonstration Project (see ch. 3) said they did not know how long services would be needed for their relative with dementia or whether they eventually would have to pay for nursing home care. Given those uncertainties, they were reluctant to spend even $10 a week for respite services (291).

Many other perceptions and feelings of people with dementia and their caregivers also are barriers to their use of services. As noted earlier, people with dementia frequently do not recognize their impairments and do not know they need services. In addition, many of them have been or are afraid they will be exploited by service providers, especially nonprofessional in-home workers (286,934). Paranoia and suspiciousness, present in one-fourth to one-half of all people with dementia, exacerbate those fears. Some people with dementia isolate themselves from everyone, including service providers, because they are afraid that if anyone finds out how poorly they are managing, they will be put in a nursing home.

Families and other informal caregivers may be reluctant to use services for many reasons. Some informal caregivers do not perceive a need for services, either because they do not feel burdened by the demands of caregiving, or because they do not regard the person with dementia as being sick or having a disease. Many caregivers also feel that they should provide all the patient's care themselves and that it is wrong to turn to outsiders for help (514,670,933). Others fear that people will criticize them for shirking their obligation to the patient if they use paid services. Such criticisms or even the anticipation of them discourage caregivers from using services (514,936).

Caring for a person with dementia may require few skills that informal caregivers do not have, although often it requires all their time and energy. As a result, some caregivers feel guilty about using services they could—at least in theory—provide themselves. Others feel—often realistically—that no one can take as good care of the person as they can.

Some family caregivers do not use services because they are embarrassed about patient behaviors, such as hallucinations, delusions, and agitation, that suggest the patient is mentally ill, and they want to conceal the behaviors from other people, including service providers (72,291,533,936). Others are afraid that the patient will be upset by new services or that the service providers will not be capable of caring for the patient. Caregivers who have a bad experience with one provider often are reluctant to try again (88,117,186,291,533,670,936). Some caregivers are so overwhelmed by feelings of sadness, guilt, frustration, and anxiety that they cannot think clearly about how services might benefit them or the patient (88,137,201,533, 610,916,936). Lastly, some caregivers feel uncomfortable about making decisions for the patient, including decisions about the use of services (533,669).

For any of those reasons, some people with dementia and some caregivers never use paid services other than physicians' services. Others eventually use services, but not until long after the time when an objective observer would have

Photo credit: Peter Carroll

Some caregivers do not use services because they feel—often realistically—that no one will take as good care of the person with dementia as they can.

said they needed help. By that time, their need for help is so great and so immediate that the process of locating and arranging services takes place in an atmosphere of crisis. Moreover, even though by then the patients and caregivers need help immediately, the feelings and perceptions that made them reluctant to use services before often have not been resolved. As a result, they are ambivalent and emotionally conflicted, which further complicates the linking process.

Some people with dementia and informal caregivers who do not use services do not need them. Others who say that they do not need services—or that they do not need services "yet"—probably do need the services for the well-being and safety of the patient and the well-being of the caregiver (88,514). It is unclear whether or to what extent public or private agencies, individual health care and social service professionals, service providers, or even family members should encourage patients and caregivers to use services that they say they do not want or need. On the one hand, encouraging people who say they do not want services to use them seems absurd when there are not enough services to meet the needs of people who are asking for them. On the other hand, some commentators have noted that it is often the most isolated patients and objectively burdened caregivers who say they do not want or need services (88,291,688). One might argue that those patients and caregivers are more in need of services than other patients and caregivers and that society should reach out to help them.

FRAMEWORK FOR AN EFFECTIVE SYSTEM TO LINK PEOPLE WITH DEMENTIA TO SERVICES

The characteristics of people with dementia, of the family and other informal caregivers of such people (if they have any), and of the service environment that were discussed in the preceding sections imply certain requirements for an effective linking system. This section discusses the essential components and criteria for such a system. Figure 1-1 illustrates those components and criteria.

Four Essential Components of an Effective Linking System

Drawing on the information presented in the preceding sections and in chapters 2 and 3 of this report and on their own knowledge about and experience in working with people with dementia, the advisory panel for this OTA study concluded that an effective system to link people with dementia to services must include four components:

- public education,
- information and referral,
- outreach, and
- case management.

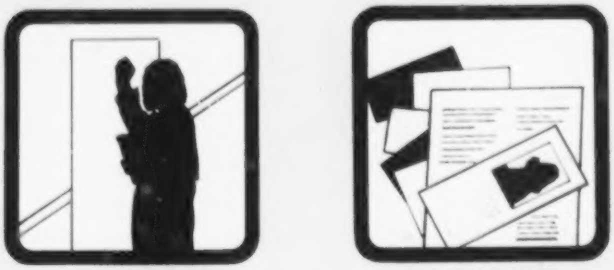
Before reaching that conclusion, the OTA advisory panel considered and ruled out other possible components, such as diagnosis; caregiver education, training, and counseling; and legal and financial services. The panel determined that although these services are important for people with dementia, they are not essential components of an effective linking system and that patients and their families could be referred

Figure 1-1—Essential Components and Criteria for an Effective System To Link People With Dementia to Services

Components of an Effective Linking System

The system must provide:

Information and referral **Case management**



Outreach **Public education**

Criteria for an Effective Linking System

The system must be:
- easily identifiable nationwide
- available throughout the patient's illness
- able to work with people with dementia who have no informal caregiver
- able to serve long-distance caregivers
- informed about available services and funding for services for people with dementia
- "dementia-friendly" and "dementia-capable."

SOURCE: Office of Technology Assessment, 1990.

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by the linking system to other agencies, organizations, and individuals that provide the services.

The OTA advisory panel also ruled out a linking system that left out any of the four components cited above—for example, a system that provided only information and referral. Lastly, the panel considered whether the four components must be provided by a single agency or whether a consortium of agencies could provide them effectively. The panel concluded that a consortium of agencies could constitute an effective linking system if a genuine connection existed among the agencies so that clients would not "fall through the cracks," as they often do now.

Public education, in the context of this report, means providing programs and materials to help people understand dementia and the kinds of services that may be helpful for individuals with dementia. Such programs and materials include pamphlets, articles, newsletters, and other publications; posters, press releases, and public service advertising in various media; radio and television programs; audiotapes and videotapes; teaching packets and curricula; and lectures, community meetings, and conferences.

Information and referral, in the context of this report, means providing information about and referrals to specific services and sources of funding for services in a community. The process can occur by telephone or in person.

As noted earlier, caregiver's lack of knowledge about services is one of the major reasons that people with dementia do not use services. Both public education and information and referral are needed to increase people's knowledge of services. Public education programs and materials are likely to increase service consciousness, i.e., general awareness of services, among the people they reach and therefore increase the likelihood that those people will search for information about specific services when the need arises. Public education programs and materials usually do not provide information about specific services. Information and referral programs do provide information about specific services in a community and therefore are likely to increase service knowledge. Information and referral programs can only assist people who contact them, however, and people who lack a general awareness of services may not contact an information and referral source.

Outreach, in the context of this report, means using an active method of identifying individuals with dementia and caregivers who need assistance but are unlikely to respond to public education programs or to contact an information and referral source on their own.[5] Outreach methods to identify isolated individuals with dementia and isolated caregivers include: screening individuals at places like senior centers and senior nutrition sites; having health care and social service professionals and other service providers who interact with elderly people and their families identify people with dementia who may need help; and sending paid or volunteer workers out to apartment buildings, public housing facilities, and other sites to look for people who may need help.

The outreach method that most closely matches the needs of isolated people with dementia and isolated caregivers is a "gatekeeper program" that makes use of the observations of individuals, such as mail carriers, utility meter readers, apartment managers, police, pharmacists, grocers, and delivery people, who come into contact with many individuals in the course of their regular activities. Through a gatekeeper program, these individuals—the "gatekeepers" —are trained to identify isolated elderly people who may need assistance and to notify a central agency. That agency is responsible for contacting the person and assessing his or her need for

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[5] Some agencies and commentators use the term outreach in a sense that is different from the sense in which it is used by OTA in this report. They use it to refer to programs or services that an agency provides outside the agency. Some of these programs and services—e.g., lectures given by agency staff members to senior citizens groups or other community groups—are effective in reaching some people with dementia and their caregivers but are unlikely to reach isolated, confused patients or isolated caregivers. In the context of this report, such programs are considered public education.

Photo credit: Bill Adams

"Gatekeeper" programs in some jurisdictions rely on mail carriers and utility meter readers to identify isolated people with dementia who may need help.

assistance.[6] The first gatekeeper program in the United States was implemented in Spokane, Washington in 1978 (688). Gatekeeper programs are now in effect in many other jurisdictions (97,148,320,456,688).

Case management, in the context of this report, means a process that includes five core functions:

1. assessing a client's needs,
2. developing a plan of care,
3. arranging and coordinating services,
4. monitoring and evaluating the services delivered, and
5. reassessing the client's situation as the need arises.

Case management is widely cited as a potential solution for many problems in health care and long-term care for various client populations and various types of agencies. Different agencies and commentators use the words "case management" to mean very different things, however, and the confusion and disagreement about what case management is makes it difficult to communicate clearly about case management and its role in a linking system.

Most commentators agree that case management includes the five functions just listed (22,43,59,110,271,382,572,574,581,657,757, 769,891,902), but agreement about these five functions does not resolve the confusion and disagreement about what case management is. For one thing, some commentators believe that case management includes additional functions —notably, case finding, screening, client education, and counseling. More importantly, the implementation of the five case management functions varies depending on many factors, including the type of agency or organization providing the case management; whether the agency provides services in addition to case management; what the goals, educational background, and experience of the case manager are; and how big the case manager's caseload is. These same factors also influence the relative amount of emphasis the case manager and the agency place on each of the case management functions.

Many agencies that allocate long-term care services and funding for services use case managers to determine people's eligibility for the benefits, to authorize the services and funding, and to monitor and account for their provision and use. When case managers are responsible for these essentially administrative tasks, the five core case management functions are modified to include the tasks. For example, service arrangement is modified to include administrative procedures for authorizing services and funding. Monitoring and reevaluation are modified to include administrative procedures to recertify the client's eligibility and to account for resources used.

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[6] Some individuals have told OTA they believe that the outreach procedures used in gatekeeper programs may invade the privacy of people who are identified as potentially in need of assistance. In contrast, individuals who administer gatekeeper programs have told OTA that they have procedures for gaining the trust of a person they contact in response to notification by a gatekeeper and for obtaining at least informal consent from the person to assess his or her needs (95,689). Given the cognitive deficits of people with dementia, their capacity to give consent is problematic, and safeguards must be built into any outreach program to protect their rights.

Some descriptions of case management, particularly in agencies that allocate services and funding for services, make case management sound like a series of administrative procedures to authorize and account for services and funds in accordance with the agencies' policies and regulations. Other descriptions of case management, in those agencies and in general, emphasize its clinical features and portray the case manager more as a professional helper, problem-solver, and client advocate than as an administrator of benefits. Some commentators believe that there is a fundamental conflict between the role of the case manager as a helper, problem-solver, and advocate for the individual client and the role of the case manager as an administrator of benefits. Others believe the two roles are compatible. In practice, many case managers perceive themselves as performing both roles simultaneously and without conflict (47).

If it were possible to distinguish between case management as a clinical process and case management as an administrative process and to call one "case management" and the other something else, it would be easier for everyone to communicate clearly about case management. That distinction does not hold up in reality, however, because the two processes are completely integrated in the practice of many case managers (see ch. 3).

Because of the confusion and disagreement about what case management is, OTA tried at first to avoid using the words "case management" in this report, and to focus on the five core functions instead. That effort failed because the core functions are relevant to both clinical and administrative case management—the same words are used to describe what case managers do in both instances. OTA then tried to delineate the specific procedures that might be involved in case management, but that effort also was unsuccessful in distinguishing among different kinds of case management.

The case management cited in this report as one of the four essential components of a system to link people with dementia to services is the clinical process in which the case manager is a helper, problem-solver, and client advocate. One of the policy issues discussed in this chapter is whether a system to link people with dementia to services also should allocate services, in which instance, the case manager presumably would also have to be an administrator of benefits. Alternatively, each client could have two case managers, one of whom is an advocate and helper, and the other is an administrator and allocator of benefits. These options are discussed later in the chapter.

It is important to emphasize that not all people with dementia and their caregivers need outreach and case management. Outreach is needed only for very isolated patients and caregivers. Case management is likely to be needed at least at some points in the course of their illness by all people with dementia who live alone and have no relative or friend to help them. Case management is also likely to be needed by some individuals with dementia who have an informal caregiver, for example, those whose caregivers are unable to define their service needs, reluctant to use needed services, or unable to arrange services for any reason. Because of the complexity and fragmentation of the service environment in many communities, individuals with dementia who need several different services may need a case manager to arrange and coordinate the services of multiple providers. On the other hand, some families and other informal caregivers function as case managers themselves (85,92,110,467,477,753,778), and more caregivers might be able to do so if accurate information about services and about funding for services were readily available.

Criteria for an Effective Linking System

Many criteria for an effective system to link people with dementia to services have been suggested in the previous sections. The most important of those criteria are reviewed here:

- The agencies that constitute the linking system must be uniformly identifiable throughout the country—perhaps by the use of a common name, logo, or telephone number—so that people know whom to call for assistance in locating and arranging services.
- Because certain services (e.g., accurate diagnosis and legal services) are needed early in the patient's illness and because the service needs of people with dementia change over time, the linking system must be available to individuals with dementia and their caregivers throughout the course of the patient's illness.
- The system must be able to work with families and other informal caregivers and with people with dementia who live alone and have no one to help them.
- The system must be able to serve long-distance caregivers.
- The agencies that constitute the linking system must develop and maintain an accurate list of services and sources of funding for services that encompasses all the kinds of services that may be needed for people with dementia, including services provided by each of the broad systems of agencies and providers (e.g., medical or physical care, mental health, social service, public health, public assistance, and aging) and any new or specialized services for people with dementia.
- The linking system must be "dementia-friendly" and "dementia-capable."

One of the policy issues discussed in this chapter is whether the linking system should serve people with dementia exclusively or should serve people with dementia and people with other diseases and conditions as well. In thinking about this issue, it is helpful to distinguish among three concepts—"dementia-friendly," "dementia-capable," and "dementia-specific." *Dementia-friendly* means the linking system is responsive to people with dementia and their caregivers. *Dementia-capable* means the system is skilled in working with people with dementia and their caregivers, knowledgeable about the kinds of services that may help them, and aware of which agencies and individuals provide such services in a community. *Dementia-specific* means the system serves only people with dementia. An effective system to link people with dementia to services must be dementia-friendly and dementia-capable, whether or not it is dementia-specific.

The components and criteria discussed in this and the preceding sections define to a great extent what it means for a linking system to be dementia-friendly and dementia-capable. Clearly, the staff of the linking system must be knowledgeable about the usual characteristics and service needs of people with dementia and their families and other informal caregivers. At the same time, the staff of the linking system must be attuned to the diversity of people with dementia and their caregivers. The staff of the linking system must be aware, for example, of the cognitive and self-care deficits typically associated with dementia and their implications for patients' service needs. To identify appropriate services for individual patients, however, the staff of the linking system also must be aware of the heterogeneity of cognitive and self-care deficits in people with dementia and the lack of correlation between cognitive and self-care deficits in some patients. Likewise, the staff of the system must be aware of the diversity among caregivers in their perceptions of the demands of caregiving and their subjective experience of burden.

As discussed in chapter 2, many agencies that provide information and referrals for people with dementia do not keep records on the people they serve by either diagnosis or condition (186,756). That agencies do not keep such records does not prove that the individual social workers, nurses, or other people who provide information and referrals for the agency are unaware of patients' diagnoses. It suggests that could be the case, however. If people with dementia are not identified as such by a linking system, they will not be referred for specialized

Photo credit: Peter Carroll

Sometimes, "being connected" to someone who knows the patient and is available to answer questions and respond to caregivers concerns is the only assistance a family wants or needs.

services even if the services are available; publications that could be helpful to the caregivers will not be provided; and common characteristics of patients that influence their service needs and the process of linking them to services may not be recognized. In order to be dementia-capable, the agencies that constitute the linking system must identify their clients with dementia as such.

As discussed in a later section of this chapter, OTA has included Alzheimer's Association chapters as one of the 11 categories of agencies that Congress could, at least in theory, designate as the basis for a national system to link people with dementia to services. For that reason, Alzheimer's Association chapters are discussed at some length in chapter 8. Regardless of any other role the Alzheimer's Association and its chapters might play in a national linking system, however, they have a clear role to play in defining what it means for a linking system to be dementia-friendly and dementia-capable. Health care and social service professionals, service providers, and others have useful ideas on this subject, but the Alzheimer's Association has been and continues to be the definitive source on the attitudes and concerns of Alzheimer's caregivers. Voluntary associations that represent people with other diseases that cause dementia and their caregivers also have a role to play in defining what a dementia-friendly and dementia-capable linking system would be. These groups should advise and monitor the system on an ongoing basis.

The Role of a Linking System as a Source of Potential Support

Many researchers and clinicians have commented on the importance to caregivers of "being connected" to someone who knows the patient and the caregiver and is available to answer questions about the patient's condition and respond to the caregivers' concerns (257,412,483,610,934). Sometimes, that person is a physician, but it may be anyone who is knowledgeable about dementia and sensitive to caregivers' concerns.

Sometimes, "being connected"—referred to as *potential support* by one research group (610)—is the only assistance a family wants or needs. Yet many agencies and individuals who work with people with dementia do not have a mechanism for providing that assistance on an ongoing basis, in large part because there is no public or private funding for it. As a result, they are only able to meet caregivers' need to be connected in the context of providing specific services for the patient.

One member of the advisory panel for this study noted that being connected often is the basis for appropriate use of services later on:

> It has been my experience that caregivers reach out often and fleetingly for information regarding potentially helpful services and programs over a period of months or years before they actually decide on help. It is quite important to have personal contact with a patient and a family—from one to three times—in order to

> do an assessment that leads to appropriate guidance, care and referrals.
>
> Often, once the visit has been done, families previously resistive to care or intervention may agree to assistance, and they also find their own funds to pay for services hitherto thought to be too expensive, unattainable, or irrelevant. The engagement of the caregiver seems to be a critical step in the process of giving care and support and one about which I have seen little or nothing documented (283).

Providing a source of potential support for patients, families, and other caregivers may be one of the most important functions of a linking system. If so, the function should be defined more clearly, differentiated from other functions of the system, such as information and referral and case management, and planned for specifically in the system.

AGENCIES, ORGANIZATIONS, AND INDIVIDUALS THAT LINK SOME PEOPLE WITH DEMENTIA TO SERVICES

Many public and private agencies and organizations, individual health care and social service professionals, service providers, and others currently provide one or more of the four functions OTA considers essential components of an effective linking system (i.e., public education, information and referral, outreach, and case management) for at least some people with dementia. Some of these agencies, organizations, and individual professionals and service providers work almost exclusively with people with dementia, and some work with people with other diseases and conditions as well. For some, linking people to services is their primary function. For others, their primary functions are providing health care, long-term care, social, or other services, and they link people to services in conjunction with providing those services.

The study conducted for OTA in Cuyahoga County, Ohio, found that many agencies provide information and referrals for people with dementia in the county.[7] OTA's contractors identified 324 agencies in the county that they thought might provide services of any kind for people with dementia and sent a questionnaire to each agency (186). Of the 97 agencies that responded, 71 said they provide information and referrals for people with dementia. No attempt was made by OTA's contractors to find out whether any of the agencies that did not respond to the questionnaire also provide information and referrals for people with dementia, and some may. Moreover, the questionnaire was not sent to voluntary associations or individual health care and social service professionals who are also potential information and referral sources. Thus, the total number of information and referral sources in the county is probably much higher.

Having a large number of agencies, organizations, and individuals that provide information and referrals for people with dementia is good in the sense that there are many places to which families and others can turn for help. On the other hand, providing information and referrals is not the primary function of many of the agencies, organizations, and individuals. Interviews with representatives of agencies that said they provide information and referrals for people with dementia in Cuyahoga County, Ohio, indicate that the agencies generally did not have comprehensive lists of services or lists of sources of funding for services (186). Since it is time-consuming to maintain an accurate list of services and funding sources, individual health care and social service professionals and service providers also are unlikely to have such lists. The large number of agencies, organizations, and individuals that provide information and referrals for people with dementia, often without an accurate resource list, increases the likelihood that people will receive wrong or only partial information about services and funding for services.

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[7] The findings of the study conducted for OTA in Cuyahoga County, Ohio, are discussed in chs. 2 and 3. A full report on the study is available from the National Technical Information Service in Springfield, VA (see app. A).

Turf issues, discussed earlier with respect to providing services for people with dementia, arise at least as strongly with respect to linking them to services. That is partly because agencies, organizations, and individual professionals and service providers perceive that whoever links people to services controls which services are used and who gets paid for providing them (46,661).

In the course of this assessment, OTA found that virtually every type of agency, organization, and individual professional and provider that works with people with dementia is aware of and concerned about the problem of locating and arranging services for them. Virtually every such agency, organization, and individual perceives itself as effectively linking some people with dementia to services, and many of them propose to solve the problem of locating and arranging services for people with dementia by expanding their role in the linking process. Often those proposals are made without consideration or even awareness of the many other types of agencies, organizations, and individuals that also link people with dementia to services.

The following subsections of this chapter describe various agencies, organizations, and individuals that provide one or more of the four functions OTA considers essential for linking people with dementia to services. The discussion is not all-inclusive. Its intent is to give a sense of the many different types of agencies, organizations, and individuals involved and the diversity of their approaches. The first subsection describes some of the private agencies, organizations, and individuals that link people to services. The second subsection describes three Federal agency programs that provide one or more linking functions for people with dementia. The following two subsections summarize OTA's findings with respect to State programs and service systems and community service systems that link people to services and the State and local agencies that implement those programs and service systems.

One of the policy issues discussed in this report is whether Congress should designate a single category of agencies nationwide to constitute a system to link people with dementia to services or, alternatively, mandate that each State designate the agencies that would make up the linking system in that State. In analyzing this issue, OTA identified 11 categories of agencies that Congress could, at least in theory, designate as the basis of a national linking system for people with dementia if Congress chose to establish a system composed of a single category of agencies. The last subsection explains how OTA identified the 11 categories of agencies and presents OTA's conclusions with respect to the current capability of any of the 11 categories of agencies to function as a national system to link people with dementia to services.[8] The information presented in the subsection on State programs and service systems that link some people with dementia to services pertains to the other alternative—i.e., that Congress could mandate that each State designate the agencies that would make up the linking system in that State.

Private Agencies, Organizations, and Individuals That Link Some People With Dementia to Services

A variety of private agencies, organizations, and individuals link some people with dementia to services or sponsor programs that do so. Examples of those agencies, organizations, and individuals are discussed in this subsection. None of these entities serves people with dementia exclusively, but all of them serve some people with dementia.

Most of the agencies in the 11 categories of agencies that Congress could, at least in theory, designate as the basis of a national linking system for people with dementia are private agencies and organizations. They are discussed at length in chapter 8 and are not discussed in this subsection.

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[8] As discussed later in this section, the 11 categories of agencies that it would be at least theoretically possible for Congress to designate as the basis of a national linking system for people with dementia are AAAs, community mental health centers, community health centers, Alzheimer's Association chapters, Family Survival Project, States' regional Alzheimer's diagnostic and assessment centers, hospital-based geriatric assessment programs, home health agencies, social health maintenance organizations (S/HMOs), On Lok Senior Health Services, and adult day centers.

Private Companies' Elder Care Programs

In recent years, concern has increased in the business community about the problems of employees who are caring for elderly relatives (233). As a result, some private companies now provide elder care programs for their employees. These programs typically furnish information about community services for elderly people and sometimes offer company employees caregiver support groups, flexible work schedules, unpaid leave to allow them to attend to caregiving responsibilities, and counseling about problems in taking care of an older person (151,443,659).

IBM has gone significantly beyond many other companies in helping its employees and retirees find services for themselves or for elderly relatives. In 1988, IBM initiated its Elder Care Referral Service, which provides information about available services, personalized counseling to help people clarify their service needs, referrals to community service providers, and short-term followup to determine whether the employee's or retiree's needs were met (116, 659,660). Work/Family Elder Directions, the private agency in Massachusetts that administers IBM's Elder Care Referral Service, subcontracts with agencies in 175 communities in which there are a significant number of IBM employees or retirees to provide the information and referral, counseling, and short-term followup that are part of the Elder Care Referral Service. IBM employees or retirees who live in other areas of the country can call Work/Family Elder Directions for assistance.

To select the agencies that would implement IBM's Elder Care Referral Service, Work/Family Elder Directions conducted a community-by-community analysis (659). That analysis led to the conclusion that there was no single category of agencies that could provide the service in all 175 communities. The agencies that eventually were selected to provide the service include AAAs, family service agencies, visiting nurse and other home health agencies, information and referral agencies (e.g., United Way information and referral), case management agencies, multipurpose senior service agencies, protective service agencies, and a few hospitals. Some of the agencies receive a basic fee intended to cover a certain number of cases at a per case rate; because they have staff and phone lines dedicated to the IBM project, those agencies receive the fee whether or not they serve the projected number of IBM clients. Other agencies get a fixed fee for each IBM client they serve. In 1988, the program served 8,100 IBM employees or retirees.

Since 1988, several other private companies have contracted with Work/Family Elder Directions for similar programs (659). These companies include Arthur Anderson and Co., Aetna Life and Casualty, several divisions of Colgate-Palmolive, Johnson and Johnson, and several divisions of CIBA-GEIGY. Other private companies have contracted with AAAs and other public and private agencies for such programs (450,577).[9]

United Seniors Health Cooperative

United Seniors Health Cooperative is a private, nonprofit organization in Washington, DC, that furnishes its members with information and assistance in obtaining services and negotiates with service providers for discounts and special services for its members. Elderly people and their families can join the cooperative for an annual fee. The cooperative was established in 1987 and, by July 1989, had 12,000 members (208). To OTA's knowledge, it is the only organization of its kind in the country.

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[9] Certain Federal Government agencies also contract for elder care programs for their employees. Since 1988, the Office of Personnel Management has contracted with a private agency in Landsdale, Pennsylvania, the Partnership Group, to provide telephone consultations, educational materials, onsite workshops, and personalized information and referrals for their employees who are caring for an elderly relative. From early 1989 to May 1990, the Social Security Administration contracted with the Partnership Group for similar assistance for its employees in 7 Southeastern States.

The cooperative provides information about services and about sources of funding for services. It has developed a computerized "Benefits Outreach and Screening Service" that identifies a person's potential eligibility for more than 50 Federal, State, and local funding programs. To use the service, an individual completes a questionnaire about his or her finances, medical condition, and other information. The information is fed into a computer, which reviews the available funding programs, identifies benefits the person is potentially eligible for, and prints out a list of those benefits and instructions on how and where to apply for them. The software package for the "Benefits Outreach and Screening Service" is available, and agencies in several areas of the country have purchased it (799). As of late 1989, the software was being adapted for use in New York State, where it will not only identify the benefits a person may be eligible for but also print out completed applications for six public programs that pay for services (208).

Connecticut Community Care, Inc.

Connecticut Community Care, Inc. (CCCI) is a private, nonprofit organization that provides case management for public agencies, corporations, foundations, and individuals in Connecticut. CCCI evolved from Triage, one of the first long-term care demonstration projects in this country (see ch. 7). When the demonstration ended, CCCI was established to continue and expand the Triage model of case management (677). OTA is aware of some other private, nonprofit case management agencies like CCCI in other parts of the country.

In 1988, CCCI expected to serve 7,000 clients, including elderly individuals referred by Connecticut's Department of Aging, AAAs, and the State Medicaid agency. Those public agencies pay CCCI on a per case basis for assessments, care planning, service arrangement and coordination, and service monitoring. CCCI allocates and arranges a wide range of health care, long-term care, social, and other services paid for by the public agencies (409,677).

In 1988, CCCI began providing case management for individuals on a fee-for-service basis (75). The organization offers comprehensive case management that includes the five core case management functions, but individuals also can purchase single case management functions, such as assessment or service coordination (see ch. 3).

Private Geriatric Case Managers

Private geriatric case managers are individual professionals (generally social workers or nurses) and others who provide client assessment, care planning, service arrangement and coordination, monitoring, and a variety of services for elderly people on a fee-for-service basis. The case management and services generally are highly personalized to respond to the individual needs of each client. Although no data are available, anecdotal evidence indicates that many clients of private geriatric case managers have dementia (136,450).

Private geriatric case managers often work independently or with one or two other case managers under the umbrella of an incorporated firm. A 1986 survey of 117 private geriatric case management firms, conducted by Interstudy, found that 65 percent of the firms employed only 1 or 2 case managers (357). Their caseloads also tended to be small—one-third worked with 10 or fewer clients per year. Most had been in business 3 years or less. Seventy percent of the firms were independent, and the remaining 30 percent were affiliated with hospitals, social service agencies, or nursing homes. Their fees ranged from $13 to $100 an hour, with 53 percent charging $50 an hour.

Private geriatric case managers sometimes are hired and paid by a relative of an elderly person, but some elderly people hire and pay a case manager themselves. More than half of the private geriatric case management firms that responded to the Interstudy survey said they provide case management for elderly people who live alone (357).

Private geriatric case managers and private geriatric case management firms often assist long distance caregivers. As of 1988, for example, Aging Network Services of Bethesda, Maryland, had developed a network of 250 social workers in communities across the country that could be hired by families or others to assist an elderly person in another locality (450).

Some private geriatric case management firms contract with public agencies to provide case management for the agencies' clients. In general, however, private geriatric case managers serve people who are ineligible for case management through public agencies because their income and assets exceed the agencies' eligibility criteria.

Elderlink

The National Association of State Units on Aging, a private association, is working with its members and other agencies to develop "Elderlink" a national telephone information and referral program for elderly people (577). The program was initiated in Illinois in 1989 (148) (see figure 1-2). The primary objective of Elderlink is to assist long-distance caregivers in locating services for a relative or friend who lives in another community (577). The planning committee for Elderlink included representatives of State units on aging and AAAs—two types of agencies that are designated by States to implement certain provisions of the Older Americans Act. State units on aging are public agencies, but AAAs include public and private agencies. If and when Elderlink is established nationwide, it is likely to reflect a partnership of public and private agencies.

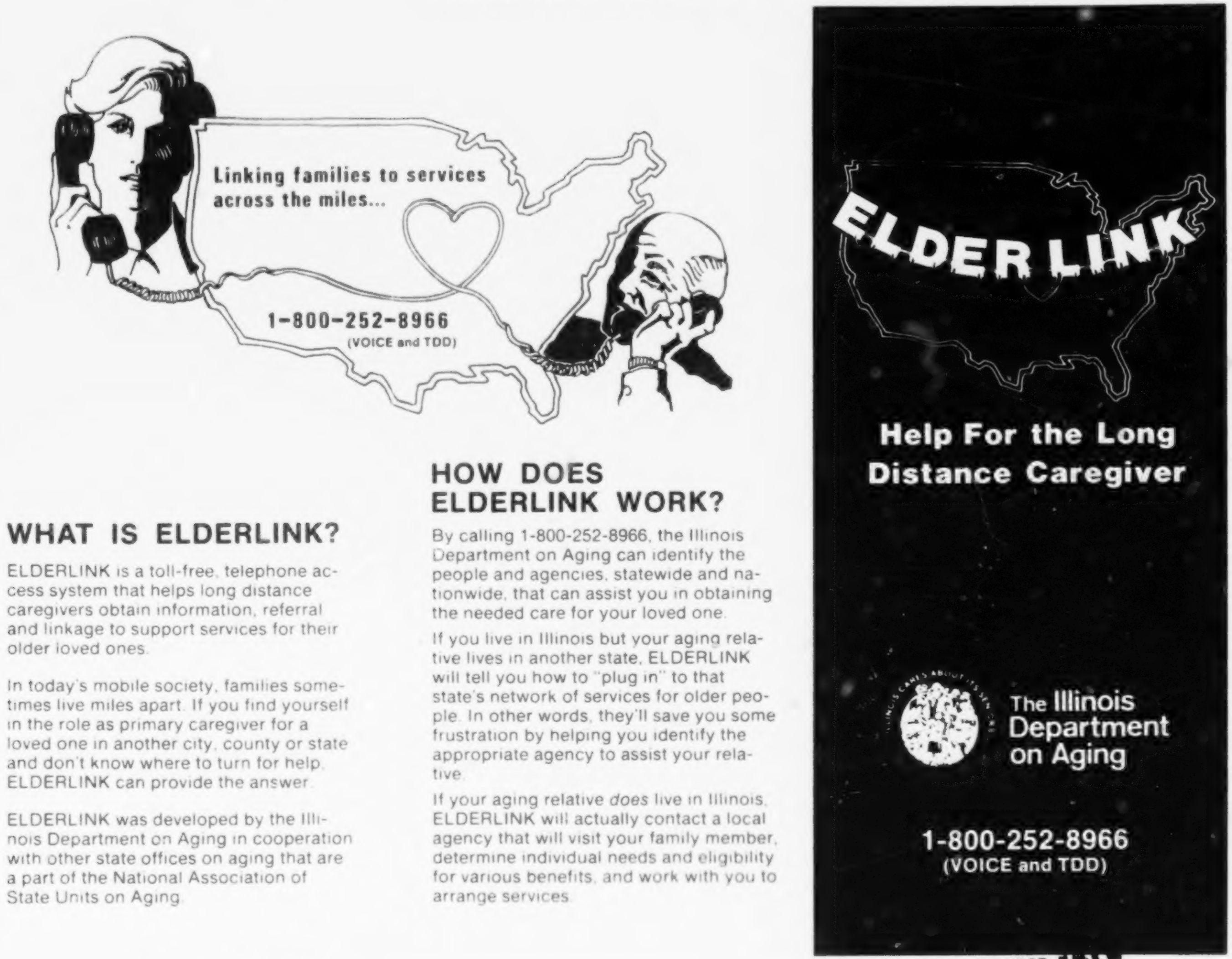
Life Care and Other Residential Care Communities and Programs

Life care communities (sometimes referred to as continuing care retirement communities) are organizations that provide housing and a variety of services for their residents in a campus-like setting or a single building (784). Typically, life care communities provide health care, long-term care, social, and other services, such as meals, transportation, and housekeeping, for their residents who need such services. Many life care communities also provide nursing home care. The provision of these services in a single setting eliminates for residents of the life care communities many of the problems in locating and arranging services that are the topic of this OTA report. Elderly individuals are usually admitted to life care communities while they are still able to function independently. As they age, some residents of life care communities undoubtedly develop dementia, but OTA is not aware of any information about the number of individuals with dementia living in life care communities.

Recently, OTA has received a number of calls from private agencies and organizations that are developing or considering developing residential care communities specifically for people with dementia. Although each agency and organization has somewhat different plans, most intend to provide apartments for people with dementia and their spouses, supportive services for the individuals and their families, adult day care, and nursing home care on the same campus. Some agencies and organizations also intend to provide a variety of services for people with dementia who do not live on the campus, e.g., diagnosis, multidimensional assessment, in-home and institutional respite care, caregiver education and counseling, and support groups. A major objective of these residential care communities is to provide a single place to which families and other caregivers can turn for help throughout the course of the patient's illness. The residential care communities are intended specifically to resolve the problem of locating and arranging services for people with dementia.

An alternative to a residential care community is the "life care at home" model of care developed by the Bigel Institute for Health Policy at Brandeis University and currently being tested in several sites with funding from the Robert Wood Johnson Foundation and the Pew Foundation (135,783). People who enroll in a "life care at home" program pay an entry

Figure 1-2—A Brochure Publicizing Elderlink, a National Telephone Information and Referral Program for Elderly People Initiated in Illinois in 1989



Linking families to services across the miles...

1-800-252-8966
(VOICE and TDD)

WHAT IS ELDERLINK?

ELDERLINK is a toll-free, telephone access system that helps long distance caregivers obtain information, referral and linkage to support services for their older loved ones.

In today's mobile society, families sometimes live miles apart. If you find yourself in the role as primary caregiver for a loved one in another city, county or state and don't know where to turn for help, ELDERLINK can provide the answer.

ELDERLINK was developed by the Illinois Department on Aging in cooperation with other state offices on aging that are a part of the National Association of State Units on Aging.

HOW DOES ELDERLINK WORK?

By calling 1-800-252-8966, the Illinois Department on Aging can identify the people and agencies, statewide and nationwide, that can assist you in obtaining the needed care for your loved one.

If you live in Illinois but your aging relative lives in another state, ELDERLINK will tell you how to "plug in" to that state's network of services for older people. In other words, they'll save you some frustration by helping you identify the appropriate agency to assist your relative.

If your aging relative *does* live in Illinois, ELDERLINK will actually contact a local agency that will visit your family member, determine individual needs and eligibility for various benefits, and work with you to arrange services.

ELDER LINK

Help For the Long Distance Caregiver

The Illinois Department on Aging

1-800-252-8966
(VOICE and TDD)

SOURCE: Illinois Department of Aging, Springfield, IL, 1989.

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fee, monthly fees, and copayments for certain services. The program, in turn, is obligated to provide a wide range of services intended to allow them to continue living at home for as long as possible. The services include nursing home care, home health aide and homemaker services, respite care, adult day care, and some routine medical care. Decisions about which services individuals receive are based on an assessment and care plan developed by a case manager. The case manager arranges any services provided by the program and helps the enrollees arrange services that are not provided by the program (e.g., transportation and home maintenance). Initially, "life care at home" sites will enroll only healthy older people, thus excluding people with dementia. For people who enroll in such a program and later become demented, however, the "life care at home" model is likely to eliminate most problems in locating and arranging services.

Federal Agency Programs That Link Some People With Dementia to Services

The Federal Government provides partial funding for many agencies and organizations that link some people with dementia to services, but the three programs described in this subsection are fully or primarily funded by Federal agencies—two by the National Institute on Aging and one by the Health Care Financing Administration. All three programs are quite new.

The Alzheimer's Disease Education and Referral Center

In 1986, Congress mandated, through Public Law 99-660, that the National Institute on Aging establish a clearinghouse to disseminate "information concerning services available for individuals with Alzheimer's disease and related dementias and their families." In 1987, the National Institute on Aging contracted for market research to determine the attitudes and knowledge about Alzheimer's disease among the general public. The results of the research show that although virtually all the individuals who participated in the research had heard of Alzheimer's disease, few had in-depth knowledge of the disease or where to go for help (850). The research participants identified several sources of information about Alzheimer's disease, notably the media, physicians, the library, hospital/community outreach programs, and local telephone health information lines (765). Most of the research participants said they preferred a local source of information because local sources are more accessible and more likely to provide personal attention, but many of them recognized the potential benefits of a national source, e.g., credibility, access to the latest research findings, and access to information about resources outside the local community.

In 1987, the National Institute on Aging contracted for a survey of Alzheimer's Association chapters to determine the number of calls received by the chapters (an average of 10 to 30 calls per month); the source of the calls (family members, social workers, respite care providers, and friends of Alzheimer's Association members); the types of information requested by callers (information about the symptoms and the progression of the disease, the latest research findings, and sources of financial assistance); the chapters' perception of the types of information needed (better financial and legal information, medication information, information on the latest research findings, information on sexuality and intimacy, and educational materials for physicians); and the chapters' perception of the best formats for that information (videotape, printed materials, large print materials, and Spanish language materials) (765). In early 1988, the National Institute on Aging convened a planning conference of experts on Alzheimer's disease education, treatment, and caregiving to determine needs and identify gaps in information dissemination (691,850).

Despite this research and planning effort, the process of establishing the mandated clearinghouse engendered many of the same turf issues and concerns discussed earlier in this chapter. The major concerns with respect to the clearinghouse pertained to the possible duplication of efforts with other organizations that already provide information about Alzheimer's disease and dementia and differences of opinion about which agency or organization is best able to provide that information.

In 1989, the National Institute on Aging awarded a contract for the operation of the mandated clearinghouse, referred to as the Alzheimer's Disease Education and Referral (ADEAR) Center. The ADEAR center will develop and maintain an online database, available to the public, that includes books, articles, and other publications and materials about Alzheimer's disease and programs for dementia patients, their caregivers, and the professionals who work with them. The center will respond to requests for information from anyone (850). It will translate the latest scientific and technical information about Alzheimer's disease into language comprehensible to the lay person, identify gaps in the current literature for the lay person, develop new publications to fill those gaps, and revise outdated publications.

The center will also set up a national toll-free telephone information line. As of April 1990, the toll-free line was not operational, but National Institute on Aging officials expected that it would be operational by the end of 1990. According to National Institute on Aging officials, callers to the toll-free line "will be provided information on the center and its services and be referred to other national and State organizations for more specific information on services in their locale" (850). The center will work with a variety of other organizations to disseminate information about Alzheimer's disease (e.g., the Alzheimer's Association, the American Association of Retired Persons, State units on aging, and AAAs).

Alzheimer's Disease Research Centers

The National Institute on Aging funds 15 Alzheimer's Disease Research Centers (ADRCs) at university medical centers nationwide. The ADRCs conduct biomedical and clinical research about Alzheimer's disease. As part of their clinical services, the ADRCs provide diagnostic evaluations and followup care for people with Alzheimer's disease. One aspect of the followup care is referrals to community services. Recently, the National Institute on Aging has encouraged the 15 ADRCs to develop satellite clinical care facilities in order to expand the number of people and geographic areas they serve.

In addition to clinical services and referrals for individuals with Alzheimer's disease, the ADRCs provide public education about dementia and the care of people with dementia. Some of the ADRCs have developed informational materials about Alzheimer's disease, and some ADRCs have cosponsored with the Administration on Aging caregiving conferences for family caregivers and other interested individuals. The staff of the ADRCs also respond to requests from the general public for information about and referrals to community services, although this is not one of the ADRCs' primary functions. OTA does not know how frequently ADRC staff members respond to calls from the general public for information about and referrals to services.

The Medicare Alzheimer's Disease Demonstration

In 1986, Congress mandated, through Public Law 99-509, that the Health Care Financing Administration conduct at least five 3-year demonstration projects to determine the effectiveness, cost, and impact of providing comprehensive services for Medicare enrollees who have Alzheimer's disease or a related disorder (504). The comprehensive services to be provided through the demonstration projects include adult day care, in-home services, and education and counseling for family caregivers. In 1988, eight demonstration sites were selected. Four of the sites are nonprofit organizations, three of which are sponsored by consortia of local agencies. The other sites include a hospital-based diagnostic and assessment program, a mental health center, a combined nursing home/community care organization, and a private, for-profit physician group practice organization. Each site is expected to enroll 500 patients, half of whom will be assigned to a control group.

Two models of care are being tested: one model in which the demonstration sites receive up to $300 a month for services for each patient, and each case manager works with 100 patients, and another model in which the demonstration sites receive up to $500 a month for services for each patient, and each case manager works with 30 patients. The case managers are responsible for arranging and coordinating services for the patients. Patients and their families must pay for 20 percent of the cost of services covered by the demonstration projects.

As of June 1990, most of the demonstration sites were still enrolling patients, and no conclusions had been reached with respect to the effectiveness, cost, or impact of the expanded services and case management. Anecdotal evidence suggests that some of the demonstration sites were having difficulty enrolling patients, particularly patients in the early stages of a dementing disease. Some observers have suggested that this difficulty may reflect a failure by some of the sites to implement effective outreach procedures to identify individuals and their caregivers who might enroll in the project. Other observers have suggested that the difficulty of enrolling patients in the early stages of a dementing illness may reflect the reluctance of families and others to acknowledge or call attention to the patient's illness.

State Programs and Service Systems That Link Some People With Dementia to Services

All States have procedures by which they link at least some people with dementia to services. In thinking about States' procedures for linking people to services, it is useful to distinguish between linking programs and service systems. As defined by OTA:

- *linking programs* are programs that perform one or more of the functions OTA concludes are essential for an effective system to connect people with dementia to services (i.e., public education, information and referral, outreach, and case management); and
- *service systems* are organizational entities that pool funds from several sources and integrate the functions of various agencies in a given geographic area in order to create a consolidated system; one function of service systems is to connect people to services.

An important difference between linking programs and service systems is that linking programs can be added to the service environment in a State or community without changing the structure, function, or relationship of existing agencies or the way services are funded. In contrast, the creation of a service system necessarily changes the structure, functions, and relationship of existing agencies and funding procedures.

Many States have programs that link at least some people with dementia to services, and some States have a service system that links some people with dementia to services. Most State linking programs and service systems are for elderly people or elderly and disabled people, in general. Recently, however, some States have developed dementia-specific linking programs. OTA is aware, for example, of at least 14 States that, in 1989, had a statewide telephone information and referral program specifically for people with dementia (see ch. 7). Missouri is one of a few States that have both a statewide telephone information and referral program for elderly people and a statewide telephone information and referral program for people with Alzheimer's disease and their caregivers (219).[10] In addition to maintaining telephone information and referral programs, some States, such as New York and New Jersey, have published resource directories for family caregivers and others that list available services for people with dementia (601,606).

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[10] Missouri's information and referral programs for elderly people and people with Alzheimer's disease are described in box 7-A in ch. 7.

Some States have developed or paid for the development of public education programs and materials about dementia and services for people with dementia. In Alaska, for example, the Older Alaskans Commission has given grants since 1984 to the Alzheimer's Disease Family Support Group (a private organization in Anchorage) to provide such programs (282,576). Additionally, public education has been one of the primary functions of the State task forces and committees that have studied the problem of Alzheimer's and other dementing diseases.

As noted earlier, gatekeeper outreach programs have been established in many jurisdictions. Often these programs are a joint initiative of the State department, division, or commission on aging, local AAAs, and utility companies (320). Illinois has a statewide system of gatekeeper programs administered by the Illinois Department on Aging and local AAAs in conjunction with several utility companies and rural cooperatives. With the addition in 1989 of Commonwealth Edison in northern Illinois, the gatekeeper programs now cover the whole State (148).

Lastly, all States have at least one program that provides case management for elderly people, although some of these programs serve very few people (354). Some States provide case management through an independent case management program; some States provide case management as a component of a program that also pays for services, such as a Medicaid 2176 Home and Community-based Waiver program (see ch. 7); and some States provide case management through several different programs. State programs that provide case management generally are not dementia-specific, but they do serve at least some people with dementia.

State programs that link some people with dementia to services are administered at the State level by different agencies in different States and by several agencies in some States. State aging agencies (departments, divisions, commissions, etc.) probably administer more of the existing linking programs than any other type of State agency, but many other types of State agencies (e.g., State departments of health, social services, or human services and State Medicaid agencies) are also involved.

At the local level, State programs that link some people with dementia to services are implemented by numerous kinds of agencies, including local offices of various State and county departments, city government agencies, AAAs, and many types of private agencies. Often, several different local agencies are involved. In some States, programs that link some people with dementia to services are implemented by agencies that have no counterpart in other States.

The number of States that provide and/or fund linking programs that serve at least some people with dementia is impressive and is growing, but it is also true that some States do not have such programs, and some States have linking programs that only serve a small percentage of all people with dementia and their caregivers. In addition, the four functions identified by this OTA assessment as essential components of an effective linking system for people with dementia (i.e., public education, information and referral, outreach, and case management) generally are not provided through the same State program, so people with dementia can easily "fall through the cracks" between programs.

State programs that link people to services are extremely diverse. That diversity makes it difficult to design a national linking system that would build on rather than duplicate or disrupt the existing programs. If Congress mandated a single category of agencies to constitute a national linking system, that decision would undoubtedly engender resistance from State agencies that administer linking programs that would be duplicated or disrupted by the congressional mandate.

In the past 10 to 15 years, in addition to, or instead of, establishing public education, information and referral, outreach, and case management programs, some States have developed a consolidated service system. These service systems are often referred to as "long-term care systems." They generally connect their clients to a range of health care, long-term care, and social services, including services provided or paid for by the system.

States' purposes in developing consolidated service systems have been:

- to reduce the complexity and fragmentation of services;
- to connect people to the services they need;
- to limit unnecessary use of nursing home care;
- to gain control over public, and especially State, expenditures for health care and long-term care services;
- to create an organizational and administrative structure that allows for efficient and appropriate use of limited services and funds by targeting available services to the people who need them most and avoiding duplication of local agencies' efforts; and, ultimately,
- to shift some of the public funds now spent on nursing home care to in-home and community services (353,362,372,374, 587).

The development of a State service system may involve several kinds of changes in agencies and procedures at the State and community level, including:

- the designation of a single agency at the State level to administer and oversee all the Federal and State programs that pay for services;
- the designation of a single agency at the community level to administer services paid for by all Federal, State, and local government programs;
- the pooling of funds from different programs to pay for services; and
- the establishment of a uniform client assessment procedure, including the use of a common assessment instrument, for services paid for by various programs.

States' consolidated service systems include case management as a central component. The role of the case manager in such systems is often quite different from the traditional case management role in which the case manager coordinates or "brokers" services from various community agencies for an individual client; in a consolidated service system, a case manager more often administers and allocates services that are already coordinated by the structure and functions of the system.

Consolidated service systems reduce the complexity and fragmentation of the service environment for the people they serve and generally make it easier for those people to connect to appropriate services, but many of the existing State service systems do not serve all types of people with dementia. Some systems do not serve people under age 60 or 65, and many State service systems focus primarily or exclusively on low-income people and/or people with severe functional impairments.

Targeting public funds for services to low-income people and people with severe functional impairments seems entirely appropriate, but such targeting is not necessarily appropriate for linking functions. As discussed earlier, people with dementia and their families need help in linking to services at all stages of the patient's illness, including the early stages when the patient is not severely impaired. Patients and families with all levels of income and assets and patients under age 60 or 65 also need help in linking to appropriate services.

Like State linking programs, State consolidated service systems are extremely diverse. Oregon, Wisconsin, and Illinois are three States that have gone further than most in creating consolidated service systems (see ch. 7). These three States' systems have common elements—including a method of coordinating the administration of various programs at the State level and methods for coordinating local agencies' functions—but there is great diversity even in these common elements. Oregon coordinates the administration of programs at the State level through a single State agency; Wisconsin uses a human service umbrella agency; and Illinois uses an interagency coordinating committee. Likewise, in each State, different types of agencies have been designated to administer services at the local level—AAAs in Oregon, county social service departments and "County 51 boards" in Wisconsin, and home health, senior service, and a variety of other kinds of public and private agencies in Illinois (587).

Perhaps, the most important observation to be made about existing State service systems is that considerable time and effort were required to develop them, and difficult organizational and turf issues had to be resolved in the process. Most of the systems were developed incrementally. Among the obstacles they faced were:

- inflexible requirements and regulations of the Federal programs that pay for services;
- administrative and organizational characteristics of State agencies that were established in the past to implement Federal program requirements and, once established, are hard to change (436); and
- resistance from interest groups that fear that the consolidation of programs and funding sources at the State level will reduce overall funding for the client population they represent.

Linking programs are easier to establish than consolidated service systems, because, as noted earlier, linking programs can be established at the State or community level without substantially changing the structure, functions, or relationships among existing agencies and without engendering the intense organizational and turf issues that must be overcome in the process of creating a consolidated service system. On the other hand, linking programs do nothing to reduce the fundamental complexity and fragmentation of the service environment, so the problems that patients and families encounter in connecting to appropriate services because of the complexity and fragmentation of the service environment remain.

If Congress designated a single category of agencies to constitute a national linking system, States that have developed consolidated service systems would have to change their systems or, alternatively, accept the existence of several systems—an outcome they have already spent considerable time and effort to avoid. Conversely, if Congress allowed each State to select the agencies that would constitute the linking system in that State, States that have developed consolidated service systems could incorporate the components of the linking system into their existing service systems.

Community Service Systems That Link Some People With Dementia to Services

Some local communities have developed service systems that link at least some people with dementia to services. Four examples of such systems are described briefly here and at greater length in chapter 7. Two of the systems (the ones in Tulsa, Oklahoma, and Linn County, Iowa) serve elderly people in general, and two (those in northern New Hampshire and northwestern Ohio) are dementia-specific. Each of the systems was developed and is operated by a consortium of public and private agencies. A different approach to coordinating services at the community level currently being developed in Cleveland, Ohio, is also described.

In 1983, five local agencies that provided funds for in-home services in Tulsa, Oklahoma, agreed to coordinate their services by adopting uniform definitions of services and service units, pooling their funds, and jointly contracting for the services (556). Building on the success of that effort, Tulsa established the Nation's first public long-term care authority in 1987. The purpose of the authority is to create a single administrative structure to pool funds for services and coordinate service delivery. It is hoped that the authority eventually will coordinate the delivery of all services—acute and long-term services; in-home, institutional, and community-based services; and publicly and privately funded services (557). Participating in the establishment of the Long-Term Care Management Authority of Tulsa were the local AAA, the State Medicaid agency, the VA Medical Center, the city and county of Tulsa, and the local United Way agency. The first project of the authority is a pilot case management project, funded by the Administration on Aging, to provide ongoing case management for elderly Medicaid and VA clients.

A different approach to linking elderly people to services has been in effect since 1981 in Linn County, Iowa, where a consortium of local agencies that provide services for elderly people established the Linn County Case Management Project. The member agencies include the local AAA; the local mental health, family service, United Way, substance abuse, and community action agencies; two hospitals; three home health agencies; an adult day center; a senior center; and two county government agencies. The member agencies use a uniform assessment instrument to evaluate elderly clients who come to them for services. Twice a month, a case management team composed of representatives of the member agencies meets to review new cases, develop care plans, and assign responsibility for managing the care of each elderly person to one of the member agencies. In the opinion of its member agencies, the Case Management Project has reduced fragmentation and duplication of services in the county and minimized turf issues among the agencies (80,463).

A community service system that specifically links people with dementia to services was established in 1987 in northern New Hampshire by a consortium of public and private agencies that joined to create the "North Country Alzheimer's Partnership Project." Two private, nonprofit agencies—Tri-County Community Action Agency, Inc. and Crotched Mountain Community Care, Inc.—jointly provide client assessments and ongoing case management for the project. They also provide information and referrals and family caregiver education, counseling, and support services. In-home services are provided by six local home health agencies. The project provides a single entry point and coordinated service delivery for people with dementia (551,614).

The ACCESS Project in northwestern Ohio is another community service system that specifically links people with dementia to services. The ACCESS project is operated by a consortium of 10 public and private agencies that have been receiving funds from the State of Ohio since 1987 to provide case management and in-home and adult day services for people with dementia (156,196). Family Service of Northwest Ohio, a private, nonprofit agency, is the lead agency for the project. Everyone who receives services through the ACCESS project receives case management (196). ACCESS also has a strong caregiver education program. One component of the program is educational workshops conducted in various locations by the East Center for Community Health. The other component is in-home caregiver education, conducted primarily by a nurse from the Medical College of Ohio who uses a video cassette recorder and tapes about Alzheimer's disease to provide individualized caregiver education about dementia and services for people with dementia (156).

In Cleveland, Ohio, several agencies that serve elderly people, people with Alzheimer's disease, and other client populations have taken a different approach to coordinating services: the agencies have co-located on a common campus, called the Fairhill Institute for the Elderly. As of June 1990, more than 10 agencies had established offices on the campus, including the Alzheimer's Center of University Hospitals of Cleveland, the Joseph M. Foley Elder Health Center of University Hospitals of Cleveland, the Geriatric CARE Center of the Case Western Reserve School of Medicine, the Cleveland Chapter of the Alzheimer's Association, the central Cleveland office of the Benjamin Rose Institute, the Retired Senior Volunteers Program of Cleveland, and the administrative offices of Golden Age Centers of Greater Cleveland. The concept of the Fairhill Institute is that the co-location of agencies will allow elderly people, including people with dementia and their caregivers, easy access to a variety of services and will simultaneously provide opportunities for joint educational programs for the agencies' staff, encourage joint planning, and minimize competition and turf issues among the agencies.

Agencies That Might Be Designated To Constitute a National Linking System for People With Dementia

At the start of this assessment, OTA identified 11 categories of agencies that Congress could, at least in theory, designate to constitute a uniform national system to link people with dementia to services, if Congress chose to establish a system composed of a single category of agencies nationwide. The 11 categories of agencies were selected because agencies in each category currently link at least some people with dementia to services; because agencies in each category are discrete entities that could be identified and funded directly from the Federal level; and because agencies in each category are currently part of a nationwide "system" of agencies or could conceivable be expanded to serve the entire country. The categories of agencies OTA identified on the basis of these criteria are:

- area agencies on aging (AAAs),
- community mental health centers,
- community health centers,
- Alzheimer's Association chapters,
- Family Survival Project,
- States' regional Alzheimer's diagnostic and assessment centers,
- hospital-based geriatric assessment programs,
- home health agencies,
- social health maintenance organizations (S/HMOs),
- On Lok Senior Health Services, and
- adult day centers.

Some of these categories of agencies (e.g., Alzheimer's Association chapters and States' regional Alzheimer's diagnostic and assessment centers) serve only people with dementia, and others serve other people as well. Some of the categories of agencies (e.g., AAAs, Alzheimer's Association chapters, and Family Survival Project) link people to services as one of their primary functions. Others link people to services secondarily to their other functions. In addition to linking people to services, all the categories of agencies provide some kinds of services, but the specific services vary from one category of agencies to another.

Photo credit: Stan Wolf, Family Survival Project

Family Survival Project, a San Francisco-based agency, helps caregivers of brain-impaired adults locate and arrange services. Most people who contact Family Survival Project are caring for an individual with dementia.

OTA analyzed each of the 11 categories of agencies in terms of its current capability to function as the basis of a national system to link people with dementia to services. The analysis is presented in chapter 8 and is not repeated here. In chapter 8, each of the 11 categories of agencies is described briefly. The extent to which each category of agencies serves people with dementia and the extent to which each category of agencies provides public education, information and referral, outreach, and case management are discussed. Lastly, the advantages and drawbacks to designating each of the categories of agencies as the basis of a national system to link people with dementia to services are summarized.

The idea of a national linking system composed of one category of agencies nationwide is appealing because such a system would be easy to publicize, easy for families and others to remember, and readily accessible to caregivers at a distance. On the other hand, OTA's analysis of the 11 categories of agencies indicates that no single category is currently capable of functioning as an effective national system to link people with dementia to services.

In each of the 11 categories of agencies, OTA identified one or more examples of agencies that effectively link people with dementia to services. These agency examples are highlighted in chapter 8. That there is at least one such agency example for each category of agencies indicates that other agencies in the same category could be modified so that they would also effectively link people with dementia to services.

As discussed in chapter 8, each of the 11 categories of agencies has positive features that would contribute to its ability to function as an effective national system to link people with dementia to services, but each category of agencies also has drawbacks. Some of the categories of agencies generally underserve elderly people and people with dementia. Other categories of agencies that do serve people with dementia focus primarily on family caregivers and lack procedures for working with people with dementia who live alone and have no informal caregiver to help them. For several of the categories of agencies to add the linking functions they do not currently provide or expand the types of clients they serve to include people with dementia at all levels of severity and in all stages of their illness would change the agencies so greatly that their primary functions would be compromised and the agencies' unique contributions to the care of people with dementia and other client populations might be lost.

OTA's analysis suggests that a consideration even more important than any drawbacks to designating any of the specific categories of agencies, however, is that designating any single category of agencies to constitute a national linking system would duplicate and disrupt existing linking programs and service systems in many States and localities.

OTHER CONSIDERATIONS IN CREATING AN EFFECTIVE LINKING SYSTEM FOR PEOPLE WITH DEMENTIA

In addition to the components and criteria for an effective linking system discussed earlier, there are several other issues that must be considered in creating a linking system for people with dementia:

- what special procedures may be needed to link ethnic minority people with dementia to services;
- what procedures will be used to determine whether individuals are able to make decisions about services themselves, and, if not, who should make the decisions;
- whether the system will concern itself with the quality and appropriateness of services to which it links people, and if so, how;
- who will be responsible for linking veterans with dementia to VA and non-VA services; and
- how the system will relate to agencies that might be designated to administer any new, federally funded, long-term care benefits.

Each of these issues is discussed briefly in this section. The first four issues are discussed at greater length in chapters 2, 4, 5, and 6, respectively. The related policy questions are whether, in mandating a linking system that would serve people with dementia, Congress should require that the system have explicit procedures for linking ethnic minority people with dementia to services, making decisions about services, evaluating and/or assuring the quality and appropriateness of services to which it links people, and linking veterans with dementia to VA and non-VA services, and if so, what those procedures should be.

Special Problems in Linking Ethnic Minority People With Dementia to Services

Ethnic minority people constitute about one-fifth of the U.S. population. About 12 percent of all Americans are black; 6 percent are Hispanic, including people of Mexican, Puerto Rican, Cuban, and other Spanish/Hispanic origin; 1.5 percent are Asian American, including people of Chinese, Hawaiian, Korean, Philippine, Vietnamese, Cambodian, Asian Indian, and Japanese origin; and 0.6 percent are Native Americans, including Eskimo, Aleut, and American Indian people (492).

The number of people with dementia in ethnic minority groups is not known. The age-specific prevalence of Alzheimer's disease is generally believed to be the same for ethnic minority groups as for the population as a whole, but some differences in the prevalence of other diseases that cause dementia (e.g., multi-infarct disease) have been noted. For a variety of reasons, the percentage of people over age 65 is lower in ethnic minority groups than in the population as a whole, but that proportion is growing rapidly. Between 1970 and 1980, it increased 40 percent for blacks, 91 percent for Hispanics, 31 percent for Asian Americans, and 71 percent for Native Americans. This rapid growth in the age group in which dementia generally occurs portends rapid increases in the overall numbers of ethnic minority people with dementia (864).

There are long-standing concerns about limitations on access to services and underutilization of all kinds of services by ethnic minority people (26,153,159,284,432,454,553,845,861). At the start of this OTA assessment, however, no research was available on problems that interfere with the process of linking ethnic minority people with dementia to services. OTA contracted for an exploratory study to identify such problems (866). The study was conducted in Los Angeles and San Diego Counties, California, and involved interviews with black, Hispanic, Japanese, and American Indian caregivers and staff members of agencies that work with each of the groups.[11] When the interviews were complete, the contractors and OTA staff met with the interviewers and service providers for the black, Hispanic, and Japanese caregivers to discuss the results and policy implications.[12] It was not possible for OTA staff to meet with the American Indian group within the time frame of the study.

As discussed in chapter 2, the results of the exploratory study and discussions with the interviewers and service providers suggest that ethnic minority people with dementia and their caregivers have several special needs with respect to information about services and funding for services. First, some members of certain ethnic minority groups do not speak English at all or well enough to communicate about the details of service availability and funding for services. That information must be available to them in their native language.

Language is not the only problem, however. The cultural heritage, traditions, customs, and beliefs of ethnic groups create differences in how and when members of a group perceive the problem of dementia, who is expected to be the caregiver, what that individual or individuals' responsibilities are, whether formal services are acceptable, and how and when they are sought (160,315). Information about dementia and services for people with dementia must reflect awareness of those cultural differences. Cultural values and concerns also are relevant in selecting service providers for ethnic minority people with dementia. The linking system must be knowledgeable about agencies' and individual providers' capacity to work with people of different cultural backgrounds.

Demographic variables, such as income and educational background, vary both among ethnic minority groups and within a given group. Information about services for people with dementia must be tailored to economic and educational differences as well as to cultural differences.

Lastly, for cultural, demographic, and historical reasons, many ethnic minority people live in

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[11] OTA's contractors intended to include Chinese and Korean people in the study but were unsuccessful in arranging the necessary interviews.

[12] The meeting participants are listed in app. A.

Photo credit: On Lok Senior Health Services

In some communities, there are agencies that serve primarily one ethnic minority group. On Lok Senior Health Services in San Francisco serves primarily individuals of Chinese descent.

communities largely composed of members of the same group. In these communities, there is generally an infrastructure of individuals and associations recognized by the community as sources of information and assistance with a wide range of problems (380). There also may be agencies that primarily serve one ethnic group. If information about services for people with dementia is to reach patients and their caregivers, it must be available through those individuals, associations, and agencies.

The caregivers interviewed for the exploratory study conducted for OTA in Los Angeles and San Diego Counties represent only one segment of the population of caregivers of ethnic minority people with dementia—caregivers who are already connected to services of some kind (866). The service providers, interviewers, and OTA's contractors pointed out that many ethnic minority people with dementia and their caregivers are not connected to services. They said dementia frequently is not identified in ethnic minority people, sometimes because families regard patients' cognitive deficits and behavioral problems, if any, as part of normal aging, but more often because families are ashamed of some symptoms of dementia and hide the patient.

The impression of OTA's contractors and the interviewers was that the problem of dementia is only one of many health and mental health problems facing service providers in ethnic minority communities. Available resources are stretched thin, and agencies are overwhelmed by many urgent needs. Moreover, some providers are not knowledgeable about dementia or appropriate services for people with dementia (866).

The most surprising finding of the study conducted for OTA was the difficulty OTA's contractors experienced in locating ethnic minority caregivers of people with dementia who were willing to be interviewed (866). Many caregivers who were contacted were not willing to be interviewed or even to acknowledge that their relative or friend had dementia. OTA's contractors concluded that the difficulty they encountered in finding caregivers to interview was similar in some ways to the difficulty a linking system would have in connecting with ethnic minority people with dementia and their caregivers. Likewise, the method that was at least partially successful for the researchers—working through the ethnic minority community infrastructure and ethnic minority agencies—is probably the best way for a linking system to connect with those people. Some patients and their caregivers are not in contact with the community infrastructure or ethnic minority agencies, however. Other outreach methods would be needed to connect with them.

Ethnic minority groups are distinguished by differences in language (if any), culture, demographic factors, and by people's awareness that they are part of the group. Although language differences usually are not a factor for nonminority people, all Americans have a cultural background and demographic characteristics that are likely to affect their perceptions of dementia, their expectations about caregiving responsibilities, and their attitudes about the use of formal services. Clearly, a system to link people with dementia to services should be responsive to the diverse perceptions, expectations, and attitudes of both minority and nonminority people with dementia and their caregivers.

Questions About Making Decisions About Services for People With Dementia

Cognitive deficits associated with dementia affect the capacity of people with dementia to make decisions about services for themselves and raise difficult questions about how their capacity to make decisions should be determined and how decisions should be made for people who are not capable of making decisions for themselves. Those questions often are obscured by the practical difficulties involved in locating and arranging services in a complex service environment and by the severe time constraints within which decisions about services must be made in many instances. Nevertheless, the questions are inherent and unavoidable in the process of linking people with dementia to services. Every agency and individual that arranges services for people with dementia answers them in some way—either explicitly, with formal or informal procedures for determining decisionmaking capacity and making decisions for clients who are not capable of deciding for themselves, or implicitly, by the way such decisions are made. The way the questions are answered involves fundamental legal rights of the patient and complex legal and ethical issues. The rights and issues are at stake whether or not the individuals who make or participate in the decisions are aware of them.

Most agencies that arrange services for people with dementia do not have explicit procedures either for determining clients' decisionmaking capacity or for making decisions (or designating someone to make decisions) for clients who are not capable of making decisions for themselves (see ch. 4). Individual case managers and others who work directly with clients necessarily act on judgments about their clients' decisionmaking capacity and about who should make decisions for clients that are not capable of deciding for themselves, but the case managers and others may not be conscious of making such judgments or knowledgeable about the implications of the judgments.

If an agency or individual that arranges services for people with dementia is unaware of the legal rights and legal and ethical issues involved in decisionmaking, those rights and issues will not receive adequate attention. Having explicit procedures for determining decisionmaking capacity and making decisions for clients who are not capable of making decisions for themselves does not guarantee that people with dementia who are capable of making decisions always will be given the opportunity to make them or that the right surrogate decisionmaker always will be chosen. Having such procedures does focus attention on the legal rights and legal and ethical issues at stake in decisionmaking and makes it more likely that those rights and issues will be considered in the way decisions about services are made.

If Congress mandated a national system to link people with dementia to services, Congress could require the agencies that constitute the system to have explicit procedures for determining decisionmaking capacity and making decisions (or designating someone to make decisions) for people who are not capable of making decisions for themselves. In establishing such procedures, agencies would have to address many difficult questions, including:

- What criteria should be used to determine decisionmaking capacity?

Photo credit: Alzheimer's Association and Rush-Presbyterian/St. Luke's Medical Center

The process of connecting an individual with dementia to services often involves difficult judgments about whether the individual is capable of making decisions about services for herself or himself and, if not, who should make the decisions.

- Who should be involved in determining a person's decisionmaking capacity?
- What procedures should be used to enhance the decisionmaking capacity of individuals with dementia, while at the same time protecting decisionally incapable individuals from potentially harmful decisions?
- How should surrogate decisionmakers be selected?
- What procedures should be followed when a decisionally incapable person's relatives disagree about which one of them should be the surrogate decisionmaker?
- How should nonfamily caregivers be involved in decisions about services for the individual they are caring for?
- What criteria should guide surrogate decisions?
- Under what circumstances should the agencies refer an individual for formal guardianship?

One of the most difficult questions faced by any agency or individual that links people with dementia to services is the relative importance that should be given to the needs, preferences, and best interests of the family v. the patient's needs, preferences, and best interests. In 1983 and 1984, a Wisconsin program, Consumer Directed Services (CDS) Initiative, gave 70 individuals with chronic disabilities, including some people with dementia, vouchers to purchase services. Each participant—called a "consumer" by the project—had a service coordinator, whose job it was to help the person define his or her service needs and select services. According to the project final report:

> One of the first questions all CDS staff had to grapple with was "who is the consumer?" This question arose when the person in need of long term support had significantly diminished mental capabilities and when family members and other natural supporters were deeply involved in providing direct support to the person.
>
> It was in these instances that CDS staff had the greatest difficulty in sorting out the interests of the consumers from the interests of the family. Frequently, there were competing interests within the family. It may seem obvious that the consumer in such a situation is the disabled person, and that CDS staff should have focused on facilitating that person's interests. In doing extended assessments of people's situations, however, CDS staff found that involvement of the family and other support network members was so vital an element that their interests could not be separated from those of the disabled person (919).

Chapter 4 discusses the question, "who is the consumer?" (or "who is the client?") and discusses the implications of various answers to the question with respect to decisions about services for people with dementia.

Further analysis and debate is needed about many of the difficult questions about decisionmaking that are inherent in the process of linking people with dementia to service. In addition, case managers and others who participate in the linking process probably would benefit from training about the legal rights, legal and ethical issues, and clinical considerations involved in the way judgments are made about an individual's decisionmaking capacity and about who should make decisions for people who are determined to be decisionally incapable.

Determining the Quality and Appropriateness of Available Services

The quality and appropriateness of all kinds of services that may be used for people with dementia vary greatly from one agency and individual service provider to another. Because of their cognitive deficits, people with dementia are particularly vulnerable to inappropriate or poor-quality care. They may be unable to identify or articulate their care needs, to evaluate the services they receive, to remember and report instances of poor care, or to be believed. Families and other informal caregivers realize that people with dementia are vulnerable, and they are often extremely concerned about the quality and appropriateness of services they may use for their relative or friend with dementia.

Books, pamphlets, and articles about services for people with dementia suggest that families and other informal caregivers are responsible for selecting good services and that information about the quality and appropriateness of available services—on which they could base their selection—is available from a variety of sources, including relatives, friends, and acquaintances who have used the services; physicians, nurses, social workers, and other health care and social service professionals; professional and provider associations, the Alzheimer's Association, caregiver support groups, information and referral agencies, hospital discharge planners, case managers, long-term care ombudsmen, AAAs and other aging network agencies, various State and local government agencies, and government regulatory programs. OTA's analysis indicates that accurate information about the quality and appropriateness of services is sometimes available from most of these sources but is not consistently available from any of them (see ch. 5). Moreover, obtaining accurate information about the quality and appropriateness of service from those sources may take time and abilities that people with dementia and some informal caregivers do not have.

A linking system could take several different approaches in addressing the difficulties people have in obtaining accurate information about the quality and appropriateness of services. It could refer patients and families to specific sources of information about quality and appropriateness; it could provide patients and families with information about the quality and appropriateness of services it refers people to or arranges for them; it could refer patients and families to or arrange for them only services that meet certain standards of quality and appropriateness; or, if the linking system provides services, it could assure the quality and appropriateness of those services directly. All these alternatives presuppose that there are accepted criteria for evaluating the quality and appropriateness of services for people with dementia and that information about quality and appropriateness is available somewhere. As discussed in chapter 5, however, many conceptual and practical difficulties in defining and evaluating quality and determining what makes services appropriate for people with dementia hinder the development of such criteria and information.

In the public debate about services for people with dementia, concerns about the quality and appropriateness of services are often considered secondary to concerns about the insufficient availability of services. Some health care and social service professionals, case managers, government planners, policy analysts, and others whom OTA asked about evaluating the quality of services for people with dementia responded that there is often no choice about services. In many localities, they said, families are lucky if there are any services available—let alone services that are appropriate for a person with dementia and of high quality.

Certainly, the concern about insufficient availability of services is legitimate. On the other hand, even when services are available, families' concerns about the quality and appropriateness of services are sometimes the determining factor in their decisions about whether or not to use the services. In the view of some families in some situations, services that are available but of poor quality or inappropriate for the patient may just as well not exist.

The best approach to helping families and others locate good services depends in part on which agencies are designated to constitute the linking system. Conversely, it would be unwise to designate for this purpose agencies that, for any reason, cannot either provide patients, families, and others with information about quality and appropriateness or assure directly the quality of services it links them to. These considerations are discussed in chapter 5. Also discussed there is the unresolved question of the role of a linking system with respect to the quality and appropriateness of services to which it links people with dementia who have no relative or friend to help them and would not be capable of using information to evaluate services for themselves, even if the information were available.

Linking Veterans With Dementia to VA and Non-VA Services

By the year 2000, there will be 9 million veterans over age 65, including two-thirds of all American men over age 65 (854). As the number of elderly veterans increases, so will the number of veterans with dementia. The VA estimates that there will be 600,000 veterans with dementia by the year 2000 (76).

The VA operates the largest health care system in the United States and currently provides many of the kinds of services that may be needed for veterans with dementia. Those services include acute medical care, diagnostic and assessment services, nursing home care, domiciliary care, hospital-based home care, adult day health care, institutional respite care, and some specialized services for individuals with dementia. In the course of this assessment, one OTA staff member visited several VA medical centers that are providing specialized services for veterans with dementia, some of which are described in chapter 6.

Not all health care and health-related services that are needed for veterans with dementia are available through the VA, however. Some services, such as in-home respite care are not provided by the VA at all. Other services are provided only at certain VA medical centers. As of 1989, for example, 100 of the 172 VA medical centers provided institutional respite care, and only 15 of the 172 VA medical centers provided adult day health care (837). Moreover, most VA health care and health-related services are provided at VA medical centers. Since the 172 VA medical centers are not uniformly distributed across the country, and since some have very large catchment areas, veterans and their caregivers may have to travel long distances to obtain VA services, and some may not be able to obtain the services (481,662,724,823). Lastly, many VA services are furnished on a "space available" basis, so that even if the services a veteran needs are provided by a VA medical center the veteran can reach, he still may not receive the services because the programs that provide them are full.

The eligibility criteria for VA services also limit access to the services for veterans with dementia. The VA has complex eligibility criteria that give highest priority for VA services to veterans with service-connected disabilities and veterans with low income (see ch. 6). Since most diseases that cause dementia occur late in an individual's life, long after he or she is discharged from military service, dementia is seldom considered a service-connected disability. Some veterans with dementia have another service-connected disability or have low income, but veterans with dementia who do not have a service-connected disability or low income generally have low priority for VA services. As a result, their chances of receiving VA services are highly dependent on whether there is "space available" in the programs that provide the services they need.

Some people believe the VA should provide all the health care and health-related services that are needed for all veterans, including veterans with dementia. Others believe that for financial and other reasons, the VA should not or cannot provide all needed services for all veterans. This OTA report does not address the questions of what services the VA should provide or for whom. It focuses instead on the processes by which veterans with dementia are (or are not) linked to the VA services for which they are eligible and to non-VA providers for services they need but cannot obtain through the VA. The report assumes that, although the amount and types of services provided by the VA and the eligibility criteria for VA services will undoubtedly change from time to time, it is unlikely that the VA will ever provide all the services that may be required by all veterans. As a result, veterans with dementia will need to be linked to both VA and non-VA services.

Problems of several kinds interfere with the process by which veterans are linked to VA services. As mentioned earlier, the eligibility criteria for VA services are complex. Veterans and their families often do not understand the criteria and may assume the veteran is not eligible for services when he is, or vice versa. They also may not be aware of potentially beneficial services provided by the VA. Many non-VA agencies and individual professionals and service providers who work with people with dementia also do not understand the VA's eligibility criteria and may not be knowledgeable about VA services, so they cannot give veterans and their families accurate information about the services, and they may fail to refer individuals to the VA who would be eligible for services. As a result, some veterans and their families never apply to the VA for services, even though the veteran is potentially eligible. Interestingly, some caregivers of veterans with dementia who were receiving good care from the VA told OTA staff that they had learned about the services completely "by accident" (see box 6-C in ch. 6).

Until recently, the VA itself has not been fully aware of the kinds of services it is providing for veterans with dementia. In 1988, the VA conducted a survey of all 172 VA medical centers to find out what programs and services were available for veterans with dementia (76). The results of the survey have been compiled into a directory for internal VA use in referring veterans and their caregivers to services and responding to public inquiries about the location of services for veterans with dementia across the country. The directory cannot solve the problem of determining whether an individual veteran with dementia will actually receive VA services, however, because that determination depends to a great extent on space availability at the time the veteran needs the services.

Other problems interfere with the process by which veterans with dementia are linked to non-VA services. According to several sources, the most difficult problem encountered by the VA in linking veterans to non-VA services is the complexity and fragmentation of non-VA services at the community level—the same problem encountered by anyone who tries to locate and arrange services in many communities (481,854, 860). Each VA medical center's Social Work Service has a community services coordinator whose job is to identify non-VA services in the community and to coordinate VA and non-VA services. The VA has also developed a software system to help the Social Work Service at each VA medical center maintain an up-to-date list of non-VA services. The community services coordinator position is staffed only half-time at many VA medical centers, however, and, as noted throughout this OTA report, the complexity and fragmentation of non-VA services in many communities make it difficult for anyone to maintain an accurate, comprehensive resource list. As a result, some VA personnel who refer veterans with dementia to non-VA services may not be aware of potentially helpful services in the community.

The Social Work Service at each VA medical center has primary responsibility for linking veterans to non-VA services through its hospital discharge planning and case management functions (see ch. 6). Although VA hospital discharge planning and case management are undoubtedly effective in connecting many veterans to non-VA services, there are two groups of veterans who may not receive the assistance they need:

- VA hospital discharge planning and case management are provided primarily, although not exclusively, for veterans who are already receiving or are eligible to receive VA services, but many veterans with dementia are unlikely to receive or to be eligible for VA services and therefore may not receive help from the VA in finding non-VA services, and
- VA case management generally is more readily available for veterans who live near a VA medical center; some VA medical centers have very large catchment areas, and many veterans in their catchment areas live far from the center; as a result, these veterans may not receive help from the VA in finding non-VA services (236).

Without effective methods for linking veterans with dementia to both VA and non-VA services, some, and probably many, veterans with dementia will not receive the services they need. As the number of veterans with dementia increases in the next decade, the demand for services for these veterans and the need for effective methods of linking for them to services will also increase. The policy issue discussed at the end of this chapter is the appropriate division of responsibility between the VA and a non-VA linking system for connecting veterans with dementia to services.

Because of the complexity of the eligibility criteria for VA services, especially as they interact with the factor of space availability, only the VA can finally link veterans to VA services. The non-VA linking system would have to be knowledgeable about VA services and eligibility requirements, however, in order to know when to refer veterans with dementia to the VA.

With regard to linking veterans with dementia to non-VA services, there are two options. If a national linking system were established, it could assume the primary responsibility for linking veterans with dementia to non-VA services. Alternatively, the VA could assume the primary responsibility for linking veterans with dementia to non-VA services. These options are discussed at the end of this chapter.

Lastly, it is clear that the VA is an important provider of services for some, and perhaps many, veterans with dementia. For that reason, the VA must be involved in the planning and operation of a national system to link people with dementia to services regardless of the specific responsibility it has for linking veterans with dementia to non-VA services.

The Relationship of the Linking System to Congressional Proposals for New Long-Term Care Benefits

As mentioned at the beginning of this chapter, several bills have been introduced in Congress in 1988, 1989, and 1990 to expand Federal funding for a variety of long-term care services. Provisions in most of the bills indicate that the agencies designated to administer the new benefits also would link people to services. This report does not evaluate any of the legislative proposals specifically. Some general statements can be made, however, about differences between the linking system discussed in this report and the linking functions that would be authorized by many of the proposed bills. First, to OTA's knowledge, none of the proposed bills include the provision of public education, information and referral, or outreach—three of the four components that OTA concludes are essential for an effective system to link people with dementia to services. Second, the case management that is part of the proposed bills would only be available to people who meet the eligibility requirements for the services to be authorized by the bills—usually impairments in two or more activities of daily living (ADLs). Presumably, anyone who received the services authorized by the proposed bills also would receive case management, since case managers would administer the services. In contrast, the case management that is a component of the linking system discussed in this report would be available to anyone who needed it, regardless of the severity of their impairments or their eligibility for any particular service. No one would be required, however, to receive case management as a condition for receiving any other assistance from the linking system.

The linking system described in this report probably would be available to more people than the number who would receive long-term care services and case management through the proposed bills, but the linking system would not provide any new funding for services. In contrast, the proposed bills would make available funding for many new long-term care services for people who met the eligibility requirements in the bills. The proposed bills would not necessarily provide: 1) information and referral for people in the early stages of dementia when referrals for accurate medical diagnosis, and legal and financial counseling are particularly important; 2) referrals for services that are not included in the bills; or 3) outreach to isolated people with dementia and caregivers who may need services but are unlikely to contact a long-term care agency on their own.

Combining the linking system discussed in this report and the expanded long-term care services delineated in the proposed bills would create a comprehensive long-term care system that would both cost more and help more people than either approach by itself. Combining the two approaches would have implications for several of the policy options discussed at the end of this chapter. First, the combined system necessarily would serve anyone who needed long-term care, not just people with dementia, but it still could be dementia-friendly and dementia-capable. Secondly, the agencies that administered the combined system necessarily would allocate services and funding for services. Lastly, some of the categories of agencies identified by OTA as potentially capable of constituting a national linking system would not be capable of administering the combined system.

Other Considerations

Six questions that are relevant to establishing an effective linking system for people with dementia but have not been discussed in this chapter are briefly reviewed here. The first is *the cost of a linking system*. That cost would vary greatly, depending on which agencies constitute the system and many other factors. The available information about the cost of some State linking programs is presented in chapter 7. Chapter 8 includes the available information about funding for the 11 categories of agencies discussed there. The figures are not necessarily comparable, however, because the linking functions and other services provided by each of the categories of agencies differ so greatly. Further analysis of the cost of a linking system will be needed once decisions have been made about which agencies will constitute the system, whether the system will serve people with dementia exclusively or other people as well, and other issues.

The second question is *the role of computer technologies in an effective linking system*. Clearly, computer technologies make it easier to maintain an accurate list of services and sources of funding for service in the complex, changing service environments that exist in many communities. The difficulty of maintaining such a list is due not to lack of computer technologies, but rather to lack of agency resources committed to updating the list, turf issues that interfere with various agencies' and individuals' willingness to cooperate in developing and maintaining the list, and problems in defining and categorizing services in a way that is relevant to the needs of patients and families. These issues are discussed in chapter 2. The computerized databases being used by some agencies and organizations that link people with dementia to services are discussed in chapters 7 and 8.

The third question is *who the case manager should be*. Virtually all health care, social service, and other human service professionals and service providers manage their clients in some sense. Nurses and social workers are the case managers in many agencies that provide the kinds of health care, long-term care, and social services that may be needed for people with dementia. State agencies that allocate long-term care services often employ as case managers individuals with a college, but not a professional degree in a human service field (47).

Differences of opinion about who should be the case manager usually focus on social workers v. nurses and involve competing claims about the knowledge and skills that case managers need and which professional group has that expertise(23,31,46,204,265,382,558,647). Those differences of opinion sometimes result in intense turf conflicts. In many agencies, however, social workers and nurses work together constructively and comfortably, learning from each other and relying on each other's special knowledge and skills. Many commentators, including some of those who have noted the turf issues between social workers and nurses, have concluded that both are needed for effective case management (23,31,409,506). That seems to be a wise conclusion. All social workers and nurses are not necessarily knowledgeable about dementia or skilled in working with people with dementia. That knowledge and those skills probably are more important in creating an effective linking system than any consistent differences between nurses and social workers as case managers.

The fourth question concerns *case management standards*. The American Nurses' Association, the National Association of Social Workers, the National Council on the Aging, at least one State, some State Units on Aging, and other organizations and individuals have formulated case (or "care") management standards (22,32,572,581). OTA has not compared those standards systematically, but a brief review indicates that they are based on similar philosophies, views about the role and functions of the case manager, and concerns about clients' rights. The requirements for a national linking system might incorporate some of the core features of those standards.

Fifth is the question of *the appropriate role of physicians in linking people with dementia to services*. As discussed in chapter 2, families and other informal caregivers of people with dementia often complain that physicians are not knowledgeable about services for people with dementia and do not refer people with dementia to appropriate services (125,257,412,479,497, 500,531,599,934). On the other hand, anecdotal evidence suggests that families and other informal caregivers may be more likely to use services if they have been referred to the services by a physician (291,931). The importance of involving physicians in the linking people with dementia to services and the difficulties involved in doing so, including constraints on physicians' time, are discussed in chapter 2.

Some commentators have suggested that people with dementia and their caregivers might be more likely to follow through on recommendations about services if the services were actually prescribed by a physician (931,944). The Alzheimer's Diagnostic and Treatment Center at the University of California/Davis Medical Center has recently developed a prescription pad for this purpose to be used by physicians in the center's service area (see figure 1-3). No information is available yet about the effectiveness of this approach.

Photo credit: M.P. Cordero-Aranda

Some, and perhaps many, families of individuals with dementia perceive themselves as the case manager for their relative with dementia and want to retain control of decisions about services for the person.

A final question concerns *family control and the role of families in relation to a linking system.* As noted in chapter 3, families of older people frequently perform various linking functions themselves, acting as an intermediary between the older person and paid service providers (85,92,110,467,477,753,778). In 1988, a study was conducted for OTA in Pennsylvania to explore the question of what is special about case management for people with dementia (934).[13] Family caregivers of people with dementia who were interviewed for that study expressed a strong desire to have control over decisions about services provided for their relative with dementia. Moreover, OTA's contractors noted that the caregivers often seemed to perceive themselves, rather than the AAA case manager who arranged services for them, as the case manager. OTA does not know whether families of people with dementia are more likely than families of nondemented elderly or disabled people to want to retain control over decisions about services for their impaired relative. In any case, allowing families to retain that control to the greatest degree possible would seem to be a worthwhile objective for a linking system. Chapter 3 discussed the role of families as "co-case managers" or "co-clients" of a linking system and other issues that pertain to the relationship between families and a linking system.

CONCLUSION

Families and others who are caring for a person with dementia often experience great difficulty locating and arranging appropriate services for the person. To some degree, this problem reflects the lack of sufficient services in many communities, the lack of adequate funding for services, the poor quality of some available services, and the lack of training for service providers. These four issues were the focus of OTA's 1987 report, *Losing a Million Minds: Confronting the Tragedy of Alzheimer's and Other Dementias*, and remain to be resolved in many, if not all, areas of the country.

The difficulty families and others have in locating and arranging appropriate services also

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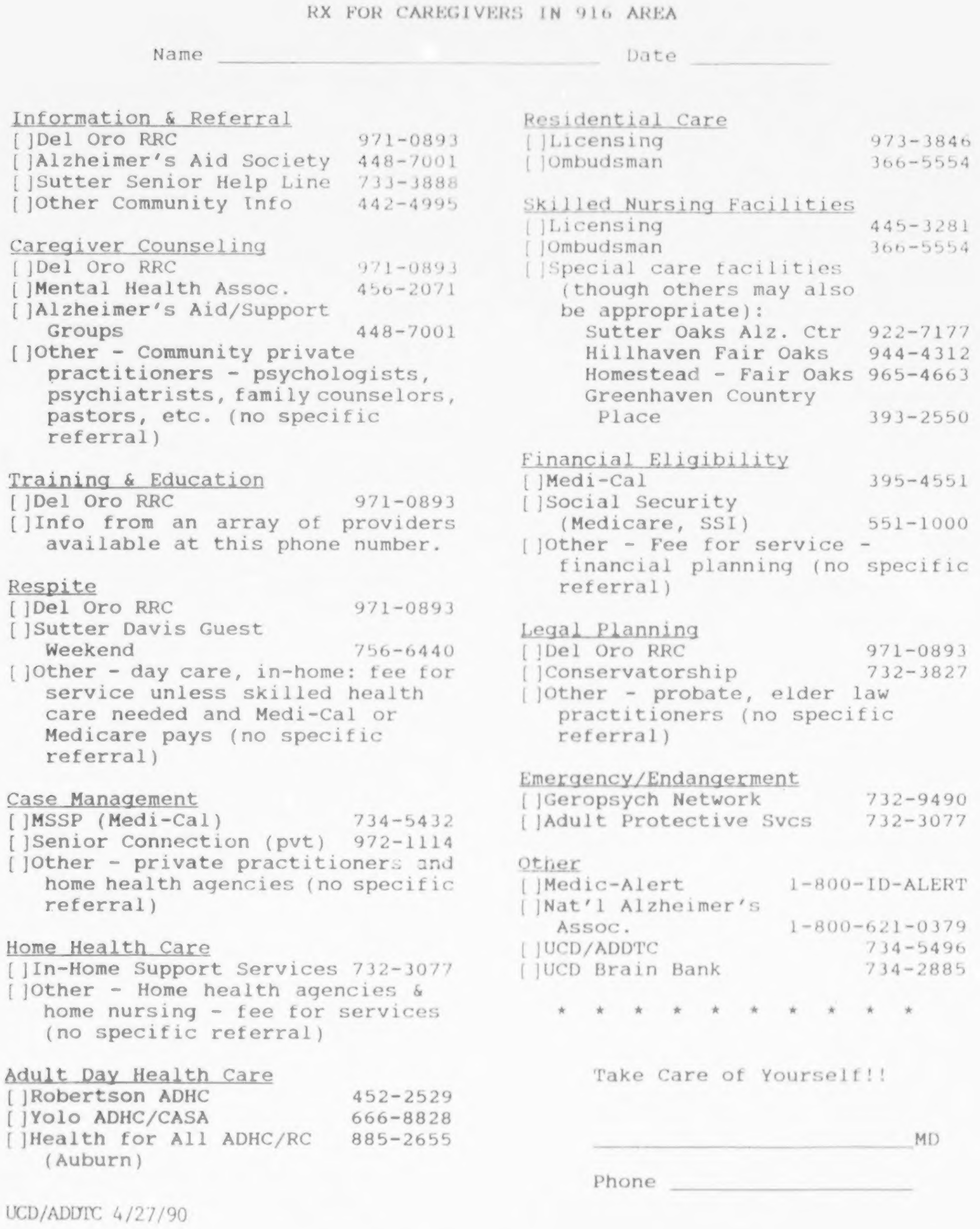
[13] The results of the study conducted for OTA in Pennsylvania are discussed in ch. 3. A complete report on the study is available from the National Technical Information Service in Springfield, VA (see app. A).

Figure 1-3—A Prescription Form for Use by Physicians in Referring Alzheimer's Patients to Community Services, 1990



RX FOR CAREGIVERS IN 916 AREA

Name ______________________ Date __________

Information & Referral

[ ]Del Oro RRC	971-0893
[ ]Alzheimer's Aid Society	448-7001
[ ]Sutter Senior Help Line	733-3888
[ ]Other Community Info	442-4995

Caregiver Counseling

[ ]Del Oro RRC	971-0893
[ ]Mental Health Assoc.	456-2071
[ ]Alzheimer's Aid/Support Groups	448-7001
[ ]Other - Community private practitioners - psychologists, psychiatrists, family counselors, pastors, etc. (no specific referral)	

Training & Education

[ ]Del Oro RRC	971-0893
[ ]Info from an array of providers available at this phone number.	

Respite

[ ]Del Oro RRC	971-0893
[ ]Sutter Davis Guest Weekend	756-6440
[ ]Other - day care, in-home: fee for service unless skilled health care needed and Medi-Cal or Medicare pays (no specific referral)	

Case Management

[ ]MSSP (Medi-Cal)	734-5432
[ ]Senior Connection (pvt)	972-1114
[ ]Other - private practitioners and home health agencies (no specific referral)	

Home Health Care

[ ]In-Home Support Services	732-3077
[ ]Other - Home health agencies & home nursing - fee for services (no specific referral)	

Adult Day Health Care

[ ]Robertson ADHC	452-2529
[ ]Yolo ADHC/CASA	666-8828
[ ]Health for All ADHC/RC (Auburn)	885-2655

UCD/ADDTC 4/27/90

Residential Care

[ ]Licensing	973-3846
[ ]Ombudsman	366-5554

Skilled Nursing Facilities

[ ]Licensing	445-3281
[ ]Ombudsman	366-5554
[ ]Special care facilities (though others may also be appropriate):	
Sutter Oaks Alz. Ctr	922-7177
Hillhaven Fair Oaks	944-4312
Homestead - Fair Oaks	965-4663
Greenhaven Country Place	393-2550

Financial Eligibility

[ ]Medi-Cal	395-4551
[ ]Social Security (Medicare, SSI)	551-1000
[ ]Other - Fee for service - financial planning (no specific referral)	

Legal Planning

[ ]Del Oro RRC	971-0893
[ ]Conservatorship	732-3827
[ ]Other - probate, elder law practitioners (no specific referral)	

Emergency/Endangerment

[ ]Geropsych Network	732-9490
[ ]Adult Protective Svcs	732-3077

Other

[ ]Medic-Alert	1-800-ID-ALERT
[ ]Nat'l Alzheimer's Assoc.	1-800-621-0379
[ ]UCD/ADDTC	734-5496
[ ]UCD Brain Bank	734-2885

* * * * * * * * * *

Take Care of Yourself!!

______________________ MD

Phone ______________________

SOURCE: Alzheimer's Diagnostic and Treatment Center, University of California/Davis Medical Center, Sacramento, CA, 1990.

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reflects several other factors, including the complexity and fragmentation of services at the community level, the difficulty of obtaining accurate information about available services and funding for services, the difficulty of coordinating the services of multiple providers, and the characteristics, feelings, and perceptions of some people with dementia and some caregivers that make them reluctant to use services, unable to define their service needs, or unable to arrange services for themselves. Even if sufficient services were available everywhere, these factors would still limit access to appropriate care for some, and perhaps many, people with dementia.

Based on an analysis of the characteristics and care needs of people with dementia, their informal caregivers (if they have any), and the service environment, OTA developed a framework for an effective system to link people with dementia to services. The essential components of the system (i.e., public education, information and referral, outreach, and case management), additional criteria, and other considerations in the development of the system have been discussed in this chapter and are analyzed in greater detail in other parts of the report.

Although the need for an effective system to link people with dementia to services is clear, establishing such a system will be difficult, largely because of turf issues. Many public and private agencies, organizations, individual professionals, and service providers currently link some people with dementia to services. With a few exceptions, each of these agencies, organizations, and individuals considers itself the right one to perform that function. Moreover, many of them propose to solve the problem of locating and arranging services for people with dementia by expanding their role in the area. Some of them are unaware of the efforts of the others to link people with dementia to services. Those that are aware of the others' efforts tend to regard those efforts, or at least any expansion of those efforts, as "duplication."

OTA was surprised by the large number of agencies, organizations, and individuals that link at least some people with dementia to services. That large number is good in the sense that there are many places to which families and others can turn for help. On the other hand, in many communities, the large number of agencies, organizations, and individuals that link people with dementia to services probably results in further complication and fragmentation of the service environment. Since many agencies, organizations, and individuals that link people with dementia to services do not have an accurate list of services and sources of funding for services, some patients and families receive wrong information or only partial information about available services and funding. Establishing an effective system to link people with dementia to services will require a consolidation of the linking functions now provided by many agencies, organizations, and individuals.

Some people who reviewed this report for OTA pointed out that it would be easier to establish a national system to link people with dementia to services if the system did not have to include case management, because many of the agencies and organizations that currently link some people with dementia to services provide public education and information and referrals but generally do not provide case management. Although it is undoubtedly true that a national linking system could be established more easily if it did not have to include case management, OTA's analysis indicates that some people with dementia would not be served effectively by such a system. People with dementia who are likely to need case management are those who live alone and have no relative or friend to help them, those who have an informal caregiver who is reluctant to use needed services or unable to arrange services, and those who need services from several different providers. OTA's analysis of available data indicates that at least 10 percent of people with dementia live alone and have no relative or friend to help them. These individuals and other individuals with dementia whose caregivers are reluctant to use needed services or unable to arrange services will not be served effectively by a linking system that provides only public education and information and referral.

Many agencies that provide services of various kinds for people with dementia provide case management in conjunction with the services—i.e., service-centered case management. An individual who is receiving case management from such an agency generally would not need long-term case management from the linking system. For such an individual, the linking system might provide only short-term case management to connect the individual to the agency originally and then be available to provide further assistance, if necessary, later on. For other individuals with dementia who need services provided by agencies that do not provide case management or services provided by multiple agencies and individuals, the linking system may have to provide ongoing case management.

A linking system is needed partly because of the complexity and fragmentation of services. If agencies' rules about whom they serve and what they provide were simpler and more flexible and the services of different agencies were better coordinated, more families and others would be able to locate and arrange appropriate services themselves.

The complexity and fragmentation of services at the community level originates to a great extent in the federally funded programs that provide or pay for services—specifically in the detailed and extensive regulations that define not only what services are covered and for whom, but also who may provide them, for how long, and in what setting. Congress repeatedly has mandated coordination among the Federal, State, and local agencies that administer these federally funded programs. Although these mandates sometimes lead to meaningful coordination, the Federal Government's own regulations often interfere with coordination at all levels of government.

In addition to establishing a system to link people with dementia to services, Congress could begin to identify and reduce the barriers to coordination and integration of services caused by Federal law and Federal regulations. This might ultimately result in consolidation of various Federal programs that fund health care, mental health, social, and other services and services for elderly and disabled people. In the short term, Congress could allow States and local governments greater flexibility to pool funds and consolidate services from different Federal programs. New federally funded services could be designed with explicit recognition of the complexity and fragmentation of existing services, and new regulations could be written in a way that will reduce, not increase this problem.

POLICY ISSUES AND OPTIONS

This OTA report discusses the need for an effective system to link people with dementia to services and presents a framework, including essential components and criteria, for such a system. Seven important policy issues with respect to the system remain to be resolved. Those policy issues and the options for congressional action are discussed in this section.

ISSUE 1: Should the linking system serve people with dementia exclusively or should it serve people with dementia and people with other diseases and conditions as well?

Option A: *Congress could mandate the establishment of a linking system that would serve people with dementia exclusively.*

Option B: *Congress could mandate the establishment of a linking system that would serve people with dementia and people with other diseases and conditions as well.*

This report identifies many special problems and concerns in linking people with dementia to appropriate services. To be effective, a linking system must be both dementia-friendly (i.e., responsive to people with dementia) and dementia-capable (i.e., staffed by people who are skilled in working with people with dementia and their caregivers, knowledgeable about the kinds of services that may help them, and aware of which agencies and individuals provide such services in the community). Some people believe that only a system that is dementia-specific could meet those requirements. They advocate the establishment of a linking system that serves people with dementia exclusively (option A).

Other people believe that individuals with dementia and their caregivers would be best served by a linking system that is not dementia-specific and that such a system could be both dementia-friendly and dementia-capable. One reason they advocate a linking system that is not dementia-specific (option B) is that some, and perhaps many, people with dementia are not identified as "people with dementia" by their families, physicians, or others. Probably this is most likely to occur if the individual has a serious physical condition in addition to his or her dementia. Families and others who do not identify the person they are caring for as a "person with dementia" are unlikely to contact a dementia-specific linking system for help in finding services. A second reason that some people advocate a linking system that is not dementia-specific is to avoid further fragmentation of the service environment by the introduction of another disease- or condition-specific element. Almost all the members of the advisory panel for this OTA assessment favored option B.

ISSUE 2: Should the Federal Government designate a single category of agencies to constitute the linking system nationwide or should each State be mandated to designate the agencies that will make up the system in that State?

Option A: *Congress could designate a single category of agencies to constitute the linking system nationwide or instruct the U.S. Department of Health and Human Services to do so.*

Option B: *Congress could mandate that each State designate the agencies that would make up the linking system in that State. Under Option B:*

1. *States could be mandated to designate a single category of agencies to make up the linking system in that State.*
2. *States could be authorized to designate either a single category of agencies, different types of agencies, or consortia of agencies in different localities, at their discretion.*

As discussed earlier, OTA identified 11 categories of agencies that might be designated to perform the linking functions nationwide. They are AAA's, community mental health centers, community health centers, Alzheimer's Association chapters, Family Survival Project, States' regional Alzheimer' diagnostic and assessment centers, hospital-based geriatric assessment programs, home health agencies, social health maintenance organizations, On Lok Senior Health Services, and adult day centers. Under Option A, Congress would designate one of those categories of agencies to constitute the linking system.

Designating a single category of agencies to constitute the linking system nationwide would make the system easy to publicize, easy for families and others to remember, and readily accessible to long-distance caregivers. OTA's analysis indicates, however, that none of the 11 categories of agencies is currently capable of constituting an effective national linking system. Each of the 11 categories of agencies has positive features that would contribute to its ability to function in that capacity, but each category of agencies also has drawbacks. Chapter 8 discusses the modifications that would be needed in each of the categories of agencies to make it an effective national system to link people with dementia to services.

By designating a single category of agencies to constitute the linking system nationwide, Congress would risk duplicating or disrupting existing State linking programs and State and community service systems. Moreover, there are significant variations from State to State and in different localities in the capacity of agencies of the same type (e.g., AAAs) to perform the four linking functions effectively. For these reasons, many people, including almost all the members of the advisory panel for this OTA study, believe that Congress should mandate that each State designate the agencies that will make up the linking system in that State (option B). One possible drawback to this option is that for political or other reasons, some States might designate agencies that would not create an effective linking system.

It should be noted that even if option B were chosen, the agencies designated by the States would have to be identifiable in some uniform way nationally, either by a uniform logo, telephone number, or some other method, so that people would know where to go for help in locating and arranging services.

ISSUE 3: Should the agencies that constitute the linking system also provide services?

Option A: *Congress could require that the system be composed of agencies that do not provide any services.*

Option B: *Congress could require that the system be composed of agencies that do not provide certain services.*

Option C: *Congress could allow the system to be composed of agencies that provide services.*

Some people believe that the same agency should not both link people to services and provide services because the agency may have a financial incentive to refer clients its own services, even if more appropriate services are available elsewhere. Other people believe that the linking functions are often performed most effectively by an agency that is also providing services and that patients and families prefer to have a service provider refer them to or help them locate and arrange other services.

The debate about whether an agency that links people to services should also provide services seldom specifies which services. Virtually all the agencies OTA studied offer at least some of the services listed in table 1-2. Option A would eliminate all those agencies—many of which effectively link some people with dementia to services—from consideration as agencies that could constitute the linking system.

Option B would specify which services agencies that constitute the linking system should not provide. Congress might decide, for example, that agencies that provide nursing home or adult day care should not be part of the linking system, whereas agencies that provide diagnosis or caregiver education and training, could be part of the linking system. On the other hand, Congress could decide that agencies that provide nursing home or adult day care could constitute the linking system, but that diagnosis and caregiver education and training should not be provided by agencies that constitute the linking system. Option C would allow agencies that provide any services to constitute the linking system.

In thinking about these options, it is helpful to distinguish between linking functions that are service-centered v. linking functions that are comprehensive. Service-centered case management connects people to services in conjunction with providing services for them. Comprehensive case management takes place independent of the provision of any particular services (657). Some agencies that provide services furnish only service-centered case management: that is, they generally provide case management only for people who are receiving or expected to receive their services. One of the main reasons why such agencies provide service-centered case management is that public and private programs that pay for services usually do not pay for case management for people who are not receiving or expected to receive services.

Agencies that provide services can provide comprehensive case management (and presumably other linking functions), as shown by the home health care and mental health agencies that provided comprehensive case management for the National Channeling Demonstration Project (30). The experience of the National Channeling Demonstration Project indicates that case managers in agencies that provide services can be effectively insulated from financial pressures to refer clients to services of their own agencies rather than more appropriate service of other agencies (30).

ISSUE 4: Should the agencies that constitute the linking system allocate services and funding for services?

Option A: *Congress could mandate that the agencies that constitute the linking system be prohibited from allocating services or funding for services.*

Option B: *Congress could mandate that the agencies that constitute the linking system be permitted to allocate services and funding for services.*

Option C: *Congress could mandate that the agencies that constitute the linking system be required to allocate services and funding for services.*

Some agencies that link people with dementia to services also allocate services and funding for services. As noted earlier, some people are opposed to having the same agency or individual case manager perform both functions because they believe the agency and the case manager will not advocate for clients and may restrict clients' access to needed services in order to limit the cost to the agency of services provided for them. They would advocate option A. Other people believe that having the same agency perform both functions creates an efficient service delivery system and that clients are much more likely to receive services when an agency or case manager has services and funding to allocate than when the agency or case manager simply arranges any available services. They would advocate option C. If the linking system were to be combined with expanded long-term care benefits, the combined system would be administered by the same agencies at the community level, and option C would have to be chosen. Option B would allow whomever designates the agencies that constitute the system to designate either type of agency.

ISSUE 5: Should the agencies that constitute the linking system be required to have explicit procedures for determining their clients' decisionmaking capacity and making decisions about services for clients who are incapable of making decisions for themselves?

Option A: *Congress could require the agencies that constitute the linking system to have explicit procedures for determining their clients' decisionmaking capacity and making decisions about services for clients who are incapable of making decisions for themselves.*

Option B: *Congress could make no requirements with respect to procedures for determining clients' decisionmaking capacity and making decisions about services for clients who are incapable of making decisions for themselves.*

Option C: *Congress could direct the U.S. Department of Health and Human Services to fund research to develop model agency procedures for determining clients' decisionmaking capacity and making decisions about services for clients who are incapable of making decisions for themselves.*

Option D: *Congress could direct the U.S. Department of Health and Human Services to develop methods for training case managers and others about the legal and ethical issues involved in the way decisions about services are made and procedures for determining clients' decisionmaking capacity and making decisions about services for clients who are incapable of making decisions for themselves.*

Option E: *Congress could direct the U.S. Department of Health and Human Services to organize and support forums for analysis and debate about unresolved issues in how decisions about services for people with dementia are and should be made.*

Fundamental legal rights and complex legal and ethical issues are involved in the way decisions about services for people with dementia are made. Yet most agencies that link people with dementia to services do not have explicit procedures for how those decisions should be made. Chapter 4 emphasizes the need for explicit agency procedures for determining clients' decisionmaking capacity and making decisions (or designating someone to make decisions) for people who are not capable of making decisions for themselves. Federal legislation to create a linking system for people with dementia could require that any agency that is part of the system have such procedures (option A). Option B would not require explicit procedures. Option C would direct the U.S. Department of Health and Human Services to fund research to develop model procedures.

Some case managers and others who participate in making decisions about services for people with dementia are not knowledgeable about the legal and ethical issues involved in how these decisions are made. Option D would direct the U.S. Department of Health and Human Services to develop appropriate methods for training case managers and others about these issues.

Some unresolved questions about decisionmaking practices, particularly the question of the relative weight to be given to the needs, preferences, and interests of the patient v. the family in decisions about services, require further analysis (see ch. 4). Option E would require the U.S. Department of Health and Human Services to organize and support forums for analysis and debate about those issues.

ISSUE 6: Should the linking system concern itself with the quality of services to which it links people with dementia, and if so, how?

Option A: *Congress could mandate that the system not concern itself with the quality of services to which it refers people, leaving that issue to clients, families, and others.*

Option B: *Congress could mandate that the system inform clients and their families about what, if any, information it will provide about the quality of available services.*

Option C: *Congress could mandate that the system inform clients and their families about which agencies and individuals that provide services are licensed, certified, and/or accredited.*

Option D: *Congress could mandate that the system refer clients only to licensed, certified, and/or accredited agencies or individual service providers.*

Option E: *Congress could mandate that the system provide clients and their families any available information about the quality of services.*

Option F: *Congress could mandate that the system control the quality of services to which it refers clients by contracting with providers that will meet certain standards and monitoring provider compliance with the standards.*

Option G: *Congress could require the U.S. Department of Health and Human Services to study the legal issues involved in providing information about the quality of services to clients of a system that links people to services. This study could determine whether there is a difference in liability incurred by a public v. private agency that provides such information and whether the form or source of the information affects liability.*

Option H: *Congress could immunize the linking system from legal liability for good faith efforts to disseminate information about the quality of services.*

As discussed in chapter 5, accurate information about the quality and appropriateness of services is not consistently available to families and others who are selecting services for people with dementia. For a variety of reasons discussed in that chapter, agencies and individual health care and social service professionals and others who refer people with dementia to services and select and arrange services for them frequently do not and/or cannot either provide information about the quality of the services or select services on the basis of quality. Option A would mandate that the linking system not concern itself with the quality and appropriateness of services it refers people to or arranges for them. Options B through F suggest various ways in which a linking system could address the question of the quality and appropriateness of services. Option G would require the Department of Health and Human Services to study the legal issues that arise when a linking system provides its clients with information about the quality and appropriateness of services. Option H would immunize the linking system from legal liability for measures it takes to inform its clients about the quality and appropriateness of services. Options B-H are not mutually exclusive.

ISSUE 7: Who should have responsibility for linking veterans with dementia to services?

Option A: *Congress could mandate that the VA have primary responsibility for linking veterans with dementia to non-VA services.*

Option B: *Congress could mandate that the non-VA linking system have primary responsibility for linking veterans with dementia to non-VA services.*

The VA provides many services that may be helpful for veterans with dementia. The complexity of the eligibility criteria for VA services, especially as they interact with the factor of space availability, means that only the VA can finally link veterans with dementia to VA services however. A non-VA linking system could not perform that function effectively, and this OTA report does not consider that possibility.

Since not all services that are needed for veterans with dementia are available through the VA, and since some veterans with dementia are not eligible for VA services, many veterans with dementia need help in locating and arranging non-VA services. Option A would assign the VA primary responsibility for linking veterans with dementia to non-VA services. Option A option would require the VA, probably through the Social Work Service at each VA medical center, to provide information and referrals to non-VA services and assistance in locating and arranging non-VA services for all veterans with dementia, including veterans who are not receiving VA services.

Since the VA Social Work Service is currently able to provide case management for certain "at risk" veterans who are not eligible for or currently receiving VA services, it is unlikely that Option A would require statutory changes. On the other hand, Option A would undoubtedly require the addition of staff to the Social Work Service at each VA medical center. In addition, each VA medical center that does not have a comprehensive list of available non-VA services would have to develop such a list and all VA medical centers would have to adopt procedures to ensure that the list is kept up-to-date.

It is also likely that VA medical centers with large catchment areas would have to assign some VA social workers to geographic areas distant from the medical center, as has been done by the Minneapolis VA Medical Center in connection with its rural case management program (see ch. 7). Lastly, the VA would have to develop outreach procedures to identify veterans with dementia who need help but are unlikely to contact the VA on their own and have no one to contact the VA for them.

Under option B, the VA would be responsible for linking veterans with dementia to VA services, and the non-VA linking system would have primary responsibility for linking veterans with dementia to non-VA services. This option would probably be easier to implement than option A, since the non-VA linking system would, once established, have the capability to serve people in all areas of the country and would have to maintain an accurate resource list to serve nonveterans anyway. The drawback to Option B is the possible duplication of case management and information and referral functions for some veterans who are receiving VA services. Procedures for minimizing such duplication of effort could probably be worked out between the VA Social Work Service and the non-VA linking system.

Part I

Considerations in Developing an Effective System for Linking People With Dementia to Services

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Chapter 2

The Need for Public Education and Information and Referral

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Chapter 2

The Need for Public Education and Information and Referral

INTRODUCTION

Many factors determine whether people with dementia and their caregivers ultimately are linked to the services they need.[1] Clearly, people cannot be linked to services or sources of funding for services that do not exist. The lack of sufficient services and funding for services for people with dementia is a major public policy concern that was emphasized in OTA's 1987 assessment *Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias* (831). Unfortunately, the ideal of having sufficient services and funding for services is not the current reality.

To avail themselves of whatever services do exist, families and others who are caring for people with dementia need accurate information about what services and funding for services are available. To plan realistically and to make informed decisions about a patient's care, these caregivers also need to know what services and funding are *not* available. Evidence reviewed in this chapter suggests that in many cases, accurate information about the availability of services and funding for services is extremely difficult to obtain. Moreover, many caregivers are unaware of potentially helpful resources.

Physicians, other health care and social service professionals, service providers, and others who work with people with dementia and their caregivers are frequently called on to advise the caregivers about services and to select and arrange services for people with dementia who have no informal caregiver to help them. In order to provide that assistance, these individuals who work with dementia patients and their caregivers also need accurate information about services and funding for services. Like families, however, they may have difficulty obtaining that information.

This chapter focuses on the informational aspects of the process by which people with dementia and their caregivers are linked to services. The first section below presents information on caregivers' views concerning the need for accurate information about services and funding for services. A subsequent section discusses deficiencies in caregivers' knowledge about services and notes the relationship between caregivers' knowledge about services and their use of services. Another section describes the information and referral process for people with dementia in a specific locality (Cuyahoga County, Ohio) and suggests seven reasons why accurate information about services and funding for services is often not available. The last three sections of this chapter address what is special about the information and referral needs of people with dementia and their caregivers, what is special about the information and referral needs of ethnic minority people with dementia, and the role of physicians in linking demented patients and their caregivers to services. At the conclusion of each major section, OTA draws implications for an effective system to link people with dementia and their caregivers to services.

On some of the topics addressed in this chapter, there is little information in the general literature. As noted in chapter 1, OTA commissioned several small, exploratory studies for this assessment in order to learn more about how people with dementia are linked to services and about problems that may arise in that process. Although the findings of these studies cannot be generalized with certainty, they do provide insights into the linking process that are useful in thinking about the characteristics of a system that would effectively connect people with dementia to services. Two of the OTA-commissioned studies—one in Cuyahoga County, Ohio (186) and the other in two counties in southern California (866)—pertain particularly to the informational aspects of the linking process and are discussed in some detail.[2]

An important conclusion that OTA draws from the analysis in this chapter is that public education and information and referral are two essential components of an effective system to link people with dementia and their caregivers to services. *Public education* in this context means providing general information to help people understand dementia and the kinds of services that may be helpful for individuals with dementia. *Information and referral* in this context means providing information about and referrals to specific services and sources of funding for services in the community.

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[1] See table 1-2 in ch. 1 for a list of the services that may be needed for people with dementia.

[2] Complete reports on the OTA-commissioned studies in Cuyahoga County and in southern California are available from the National Technical Information Service in Springfield, VA (see app. A).

Although this chapter focuses on the informational aspects of the linking process, it is important to note that some people with dementia and their caregivers are unlikely to respond to public education programs and may be unable or unwilling to contact an information and referral source on their own. OTA's analysis in chapter 3 suggests that to link some people to services, active outreach and case management are necessary. Thus, outreach and case management are also essential components of an effective system to link people with dementia to services.

Accurate information about services for people with dementia includes information about the quality of services, as well as about the availability of services and funding. Families and other caregivers want the services they may use for a person with dementia to be of acceptable quality, and their perceptions about quality may influence their decisions about using the services. Because of the importance of information about quality and because of the complexity of issues involved in evaluating the quality of services for people with dementia, a full chapter of this report (ch. 5) focuses specifically on problems in obtaining information about quality.

CAREGIVERS' VIEWS ON THE NEED FOR INFORMATION

Families and other informal caregivers of people with dementia often view the lack of accurate information about services and funding for services with frustration and consider it an important aspect of the difficulty of caring for a person with dementia. Numerous State task forces and committees that have focused on the problems of Alzheimer's disease and related dementias have noted caregivers' concerns about the lack of accurate information about services and funding (37,142,246,360,396,408, 497,500,530,537,592,599,870,920).[3] The Alzheimer's and Related Diseases Task Force in Kansas reported, for example:

> Family members and caregivers pleaded at the public hearings for information about Alzheimer's and related diseases. They pleaded for reliable referrals to services and easily accessible and up-to-date information so they could properly plan and care for their loved ones (396).

The Wisconsin Task Force on Alzheimer's Disease and Other Irreversible Dementias similarly reported:

> Alzheimer's family members often tell distressing stories about not knowing where to go for help, going from one service provider to another in a vain search for assistance, and being misinformed about availability of services or eligibility for programs (920).

Echoing similar concerns, the New Jersey Alzheimer's Disease Study Commission reported that the caregivers of people with dementia were "all too often passed from one potential information source to another without obtaining answers and/or help in identifying specific local resources" (599).

One of the specific concerns that caregivers expressed to some State task forces and committees on Alzheimer's and other dementias was that accurate information on eligibility for publicly funded programs such as Medicaid was lacking. The task forces in Maryland and Michigan noted that some caregivers had been given incorrect information about Medicaid eligibility (497,530).

Another specific concern that caregivers expressed was the lack of information about legal and financial matters related to patient care and the difficulty of finding anyone to advise them on these matters (37,99,142,246,408,497,500,530,599). One son told the Kansas Alzheimer's and Related Diseases Task Force, for example:

> We talked to 17 attorneys to find one who would accept the case. There is no one place or phone number that can answer specific questions. I have been told I am asking questions that no one has ever asked before (396).

Lastly, families and informal caregivers told State task forces and committees that many physicians were not knowledgeable about services that might benefit people with dementia and their families and did not refer them to such services (412,479,497, 500,531,592,599). Despite the fact that some caregivers told State task forces and committees about physicians who had been helpful in referring them to support groups and other services (497,500,599), many caregivers' experiences were negative. One

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[3] App. C lists reports of the State task forces and committees that have studied or are studying the problem of Alzheimer's disease and related dementias.

Photo credit: M.P. Cordero-Aranda

The difficulty of obtaining accurate information about services and funding for services is extremely frustrating for many family caregivers.

woman in Michigan said her husband's physician gave her no referrals or other advice except to "accept the fact that the patient would never be any better than he was at that time and would probably get progressively worse" and "take him home and learn to live with it" (531). A caregiver in Massachusetts said that the demented person's physician "offered no advice or any alternative other than nursing home care" (500).

In 1986, in conjunction with OTA's 1987 assessment of Alzheimer's and other dementias, a mail survey of individuals drawn from the mailing list of the national Alzheimer's Association was performed (926).[4] Survey questionnaires were mailed to a sample of 2,400 individuals, and responses were received from 569 family caregivers of people with dementia from 49 States and the District of Columbia. The responses from these 569 caregivers indicate the importance to family caregivers of information and assistance in locating services and sources of funding for services.

Part of the survey questionnaire asked respondents how important they considered 11 different types of assistance in the care of people with dementia (926). The three types of assistance considered "essential" by the largest percentages of the 569 responding family caregivers are listed below. Two of the three (those in italics) had to do with information and assistance in locating services and funding for services:

1. A paid companion who could come to the home a few hours each week to give them a rest (68 percent said that a paid companion was essential, and 96 percent indicated that it was either essential, very important, or important).
2. *Assistance in locating people or organizations that provide care for the patient* (56 percent said that such assistance was essential, and 97 percent said it was either essential, very important, or important).
3. *Assistance in applying for Medicaid, Social Security, Supplemental Security Income, etc.* (54 percent said that such assistance was essential, and 94 percent said it was either essential, very important, or important) (926).

Another study of 59 black family caregivers of people with dementia in Cleveland, Ohio, had similar findings (750). Asked what help they needed to care for their relative with dementia, the caregivers in this study said they needed the three things listed below. One of these (the item in italics) had to do with information about services and funding for services:

1. Affordable respite services.
2. Counseling to help resolve family conflicts about the patient's care.
3. *Information about Alzheimer's disease, available community resources, and sources of legal and financial assistance.*

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[4] A complete report on the 1986 mail survey conducted in conjunction with OTA's assessment is available from the National Technical Information Service in Springfield, VA (see app. A).

DEFICIENCIES IN CAREGIVERS' KNOWLEDGE ABOUT SERVICES

Many caregivers of people with dementia have limited knowledge about the availability of services that may benefit a person with dementia. One of the questions in the 1986 mail survey just mentioned pertained to caregivers' knowledge of services in their communities (926). As shown in table 2-1, the percentage of the 569 family caregivers who said a service was available or not available varied, depending on the service in question. The important finding for the discussion here, however, is that, *depending on the particular service in question, between 31 and 55 percent of the responding caregivers said they did not know whether the service was available.*

Another survey of family caregivers in 16 States asked the caregivers if they knew of any services (excluding support groups) for people with dementia in their community (117). Although 43 percent of the 597 responding caregivers said they knew of at least one community service and 21 percent said they were certain that no services were available in their area, *36 percent of the responding caregivers said they did not know whether any services were available.* Since the sample of family caregivers for this survey was drawn from the mailing lists of family support groups—and family support groups often provide caregivers with information about services (245,256,294)—the fact that more than one-third of the survey respondents did not know whether services were available in their community is surprising and indicates the extent of the problem of caregivers' lack of knowledge about services.

A third study of 93 family caregivers of people with dementia in Michigan also asked the caregivers about the availability of services in their communities (138). *Depending on the particular service in question, 14 to 58 percent of the responding caregivers said they did not know whether the service was available.* Older caregivers were more likely than younger caregivers to say they did not know whether services were available. Caregivers who were depressed (as shown by responses to a widely used depression questionnaire) were less likely than other caregivers to know whether services were available.

Table 2-1—Family Caregivers' Knowledge of Six Types of Services, 1986 (N = 569)

"As far as you know, is it possible where you live to obtain the services of"

Service	Yes	No	Don't know
Paid companion/ home health aide	52%	17%	31%
Visiting nurse	55	11	34
Nursing home care	23	36	41
Adult day care	31	26	43
Respite care	23	26	51
Domiciliary/boarding care	16	29	55

SOURCE: Yankelovich, Skelly and White/Clancy, Shulman, Inc., "Caregivers of Patients With Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, April 1986.

As mentioned earlier, OTA commissioned an exploratory study in Cuyahoga County, Ohio, to shed light on the process by which people with dementia are linked to services and the problems that may arise in that process (186).[5] That study in Cuyahoga County included in-depth interviews with 26 caregivers who contacted the telephone helpline of the Cleveland Alzheimer's Association Chapter between April and July 1988—6 spouses, 14 adult children, 4 other relatives, and 2 friends of a person with dementia. As part of the interview conducted for OTA, each of the 26 caregivers was read a list of 20 services that might be needed for a person with dementia and asked two questions with respect to each service: 1) whether he or she had heard of the service, and 2) whether he or she knew who provided it in Cuyahoga County.

As shown in figure 2-1, the only services that more than 75 percent of the 26 caregivers had heard of were home-delivered meals, adult day care, support groups, and in-home skilled nursing care (186). The remaining 25 percent of the caregivers were not familiar with these four services, and even more caregivers were not familiar with other services such as counseling, referral services, homemaker services, and case management.

For many of the services on the list, a majority of the 26 caregivers interviewed could not identify specific providers. There were no services for which more than 65 percent of the caregivers could identify a specific provider. Only half of the caregivers said they could identify a specific provider of referrals or education and information programs on dementia. Only one-third said they could identify a specific

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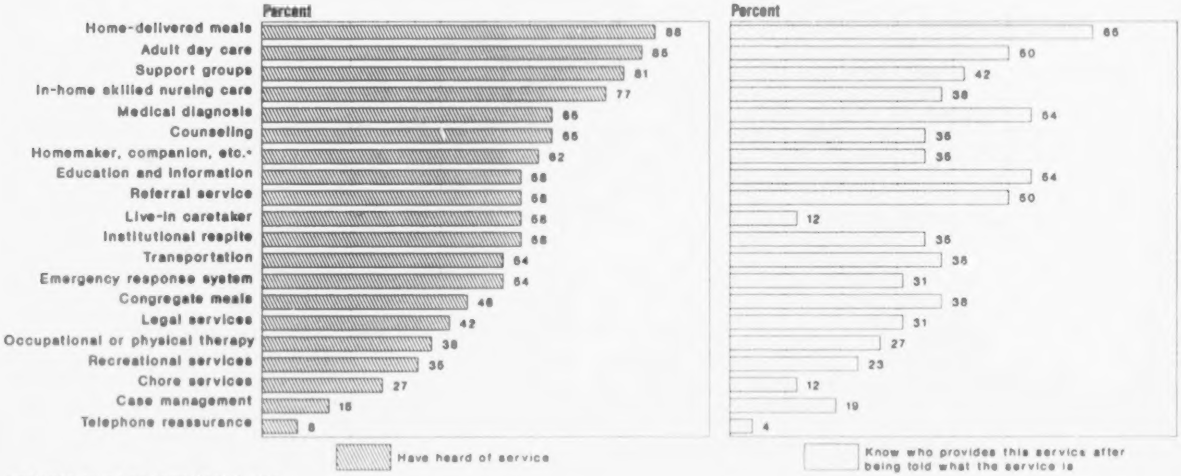
[5] All of the components of the study in Cuyahoga County, Ohio, are described in app. A.

Figure 2-1—Caregivers' Knowledge of Services in Cuyahoga County, Ohio, 1988



*Includes sitter or home health aide

SOURCE: S. Eckert and K. Smyth, "Methods of Locating and Arranging Health and Long-Term Care Services for Persons With Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, 1988.

provider of homemaker, companion, sitter, or home health aide services.

The caregivers of people with dementia who were interviewed in the exploratory study in Cuyahoga County may not be representative of caregivers of people with dementia across the country or even caregivers in Cuyahoga County. That all 26 of them were in contact with an Alzheimer's Association chapter suggests that these caregivers may be more knowledgeable about services than caregivers in general. Nevertheless, the fact that many of these 26 caregivers were unaware of services suggests that lack of knowledge about potentially helpful services is a significant problem among caregivers.

The Relationship Between Caregivers' Knowledge of Services and the Use of Services

Not all families and other informal caregivers who know about services use them. The 1986 mail survey of family caregivers that was commissioned by OTA as part of its 1987 assessment of Alzheimer's and other dementias found that, depending on the service in question, 32 to 61 percent of the family caregivers who knew about a service had used or were using the service (926). The previously mentioned survey of 597 family caregivers of people with dementia in 16 States found that 58 percent of the caregivers who knew about any community services had used at least one of them (117).

To learn more about what factors determine whether caregivers of people with dementia use services and how caregivers' knowledge of services affects their use of services, the contractors who conducted the study in Cuyahoga County asked the 26 caregivers they interviewed to give their opinions about why people do not use services (186). Each caregiver was read a list of 14 possible reasons why people might not use services and asked: 1) whether and how often each was a reason why people in general did not use a service; and 2) whether it was a reason why they themselves did not use the service.

As shown in table 2-2, the reason for not using services that was identified most frequently by the 26 caregivers in Cuyahoga County—both for people in general and for themselves—was *lack of knowledge about what services are available* (186). The reason second most frequently identified by the caregivers for themselves was inability to afford the services. The reason second most frequently identified by the caregivers for people in general was lack of knowledge about how to make arrangements to use services.

In addition to including interviews with caregivers, the study conducted for OTA in Cuyahoga County, Ohio, included in-depth interviews with representatives of 24 agencies in the county that provide information and referrals for people with dementia—4 hospitals, 2 home care agencies, 4 county and city government offices on aging, the county human service agency, 3 private social service agencies, 5 senior centers, 2 multiservice agencies, the county public library, the county information and referral agency, and a community mental health center (186). Each of the agency representatives was given a list of 15 possible reasons why people might not use services and asked to give his or her views on how often each reason keeps people with dementia and their caregivers from using services.

As shown in table 2-3, clients' *lack of knowledge about the availability of services* was identified as often or occasionally a barrier to service use by all 24 agency representatives in Cuyahoga County, Ohio (186).

There are many reasons why people do not use services. Barriers to the use of services that pertain to the personal characteristics or perceptions of people with dementia and their caregivers are discussed in chapter 3. The main point here is that the 26 informal caregivers and 24 agency representatives interviewed in the study in Cuyahoga County, Ohio, identified people's lack of knowledge about services as the single most important barrier to the use of available services. Lack of knowledge about services was identified as a barrier to the use of services more often than any other factor, including the ability to pay for services. Although the results of the study in Cuyahoga County cannot be generalized with any certainty given the small sample sizes and other aspects of the study, they do suggest that lack of knowledge about services among the caregivers of people with dementia is an important barrier to the use of available services.

The Distinction Between Service Consciousness and Service Knowledge

In thinking about the problem of caregivers' lack of knowledge about services, it is useful to distinguish between:

- general awareness of services, which some researchers call *service consciousness*; and
- knowledge about a specific service, including who provides it in a community, which some researchers call *service knowledge* (431).

As shown in figure 2-1, the study conducted for OTA in Cuyahoga County, Ohio, made that distinction explicitly and found that many of the 26 caregivers interviewed there not only lacked service knowledge (i.e., did not know of specific providers of services in the community) but also lacked service consciousness (i.e., had never even heard of some types of services) (186). Most of the other studies that have investigated caregivers' knowledge of services have not drawn any distinction between service consciousness and service knowledge; and the questions they have asked seem to pertain more to service knowledge than to service consciousness.

Despite the fact that most studies have not focused on it, caregivers' lack of service consciousness is an important aspect of the overall problem of caregivers' lack of knowledge about services. People who are generally aware of potentially beneficial services are likely to search for information about the availability of a specific service in their community when the need arises (431); people who are not generally aware of services are unlikely to search for that information.

Implications for an Effective System To Link People With Dementia to Services

Since caregivers' lack of knowledge about services is at least one of the major reasons that people with dementia and their caregivers do not use services, an effective system to link people with dementia to services must find ways of increasing caregivers' knowledge about services. In order to increase caregivers' knowledge of services, a linking system must seek to enhance both caregivers' general awareness of the kinds of services that may be helpful (i.e., service consciousness) and their knowledge of specific service providers (i.e., service knowledge) (186).

Caregivers' service consciousness can be increased by *public education programs* and materials such as those that have been developed by the Alzheimer's Association, other voluntary associations that represent people with Alzheimer's, Huntington's, or Parkinson's disease, or stroke, and some State and local government agencies. Public educa-

Table 2-2—Caregivers' Opinions About Why People Do Not Use Services, Cuyahoga County, Ohio, 1988 (N = 26)

Possible reasons why people do not use services	How often is it true for people in general? Usually	Is this a reason you did not use services? Yes
People don't know what services are available	73%	81%
People know what services are available but don't know how to make arrangements to use them	42	50
People can't afford to pay for services	38	73
People don't think they need the services recommended to them	38	50
People don't use the services because they do not want to lose their independence	38	19
The system of services for people with dementia and their families is too complicated for people to figure out	35	46
People don't recognize the fact that they need services	33	42
The kinds of services needed by people with dementia and their families aren't available in the areas where some people live	31	50
Some services needed by people with dementia and their families just aren't available	31	54
People don't have transportation to services	27	35
Using services makes people feel uncomfortable	27	31
Agencies that provide information about services and make referrals don't know enough about what services are available	27	42
People are afraid others will not approve if they use services	19	19
People have money but are not willing to pay for services	3	8

SOURCE: S. Eckert and K. Smyth, "Methods of Locating and Arranging Health and Long-Term Care Services for Persons With Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, Washington DC, 1988.

Table 2-3—Agency Representatives' Opinions About Why People Do Not Use Services, Cuyahoga County, Ohio, 1988 (N = 24)

Possible barriers	How frequently does each barrier keep potential clients from using services? Often	Occasionally
Clients don't know that services are available	75%	25%
Clients do not have adequate financial resources to pay for the service	71	16
Clients desire to remain independent of the formal care system	58	33
Services aren't available in some geographic areas	58	29
Clients don't recognize they need formal services	54	42
Clients don't have transportation to the service	54	25
The service system is too complex or fragmented for people to use	48	30
Clients don't know how to access services once they've found they're available	42	46
Clients feel the recommended service is not needed	38	46
Clients are uncomfortable using recommended services[a]	38	38
Needed services aren't offered for dementia clients	33	29
Persons providing information and referral don't have comprehensive knowledge about what services are available[b]	28	42
Clients are judged to have adequate financial resources but are unwilling to pay for services	16	42
Clients think others will disapprove of their using the recommended service	12	29
Clients' schedules or competing demands prevent their use of services	4	29

[a] One respondent (4 percent) did not answer this question.

[b] Three respondents (12 percent) did not answer this question.

SOURCE: S. Eckert and K. Smyth, "Methods of Locating and Arranging Health and Long-Term Care Services for Persons With Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, Washington DC, 1988.

tion programs and materials inform people about dementia and about the kinds of services that may be helpful for people with dementia; they generally do not give detailed information about specific agencies or individual service providers, although they frequently do give a telephone number to call for such information.

The detailed information that people need in order to select and arrange a particular service can be made available through *information and referral programs*. Information and referral programs can only assist people who contact them, however, and people who are unaware of services are unlikely to call. This observation underscores the point made earlier that an effective linking system must include public education as well as information and referral.

WHY ACCURATE INFORMATION ABOUT SERVICES AND FUNDING FOR SERVICES IS OFTEN NOT AVAILABLE

There are many anecdotes about the difficulty of obtaining accurate information about services and funding for services for people with dementia. To OTA's knowledge, however, the only research on the number and types of agencies that provide information and referrals for people with dementia and their referral procedures is the exploratory study conducted for OTA in Cuyahoga County, Ohio (186).[6]

The following discussion presents the Cuyahoga County study's findings about the information and referral process for people with dementia in the county, identifies seven reasons why accurate information about services and funding for services is often not available, and discusses the implications of those findings and reasons for an effective system to link people with dementia to services.

Although the findings in Cuyahoga County are not necessarily generalizable to other localities, they do provide a context and a basis for thinking about the problem of lack of accurate information about services and funding for services. OTA would like to emphasize that no criticism of Cuyahoga County is intended by any part of the discussion in this report. In fact, Cuyahoga County is known for its commitment to aging and human services and for the recent efforts of many organizations and individuals there to improve services and service delivery for people with dementia. Whatever problems in linking people with dementia to services can be noted in Cuyahoga County, therefore, are likely to be worse in other parts of the country. OTA is grateful to the agencies in Cuyahoga County for their participation in its study, which provides the only available data on some aspects of the information and referral process for people with dementia.

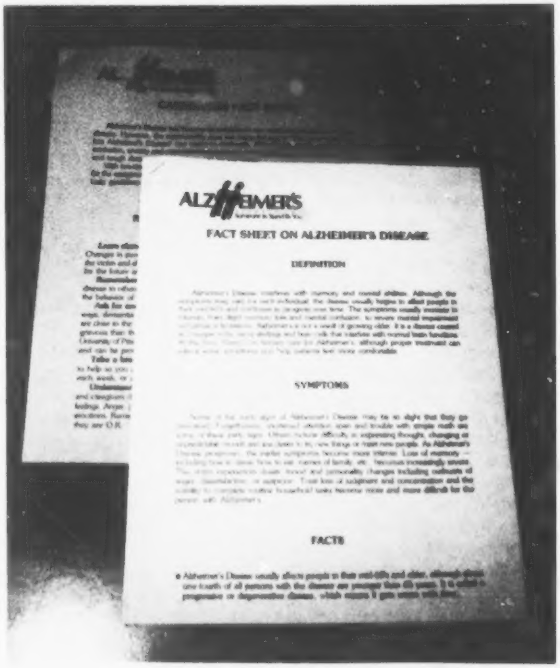


Photo credit: Bill Adams

Public education materials such as these fact sheets on Alzheimer's disease and caregiving can increase caregivers' knowledge about dementia and about the kinds of services that may be helpful for a person with dementia.

The Information and Referral Process in Cuyahoga County, Ohio

In 1987, OTA's contractors mailed a survey questionnaire to 324 public and private agencies in Cuyahoga County, Ohio, that the contractors thought might provide information and referrals or services of any kind for people with dementia (186). Ninety-seven (30 percent) of the 324 agencies responded. OTA's contractors did not make any attempt to obtain information about the 227 agencies that did not respond to the survey questionnaire.

Of the 97 agencies that responded to the survey in Cuyahoga County, 84 indicated that they did in fact provide information and referrals and/or services for people with dementia—8 hospitals, 9 nursing homes, 11 home care agencies, 2 adult day centers, 10 local government agencies, 3 social service agencies, 21 senior centers or programs, 2 multiservice agencies, 10 referral agencies, and 8 other types of agencies (186).

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[6] A complete report on the study in Cuyahoga County is available from the National Technical Information Service in Springfield, VA (see app. A).

Of these 84, 75 agencies (including agencies of all the types just listed) indicated that they do provide information and referrals for people with dementia in Cuyahoga County. Some of the 75 agencies (e.g., referral agencies) provide information and referrals as their primary function, and others (e.g., hospitals, nursing homes, senior centers) provide information and referrals as a secondary function. Sixty-three of the 75 agencies said that they provide information and referrals for people with dementia who are not receiving any services from the agency; presumably, the other agencies provide information and referrals only for people with dementia who are receiving services from the agency.

As noted earlier, OTA's contractors conducted in-depth interviews with representatives of 24 of the 75 agencies that said they provide information and referrals for people with dementia (186). According to these agency representatives, many of the 24 agencies provide information and referrals for people with dementia both over the telephone and in person. They tell people about available services and give them the names and telephone numbers of specific service providers. Many of the agencies also hand out or mail printed educational materials, including Alzheimer's Association brochures, other pamphlets and articles on dementia, lists of nursing homes and other types of agencies, and the names and telephone numbers of agencies and contact people within those agencies. One agency representative noted, "We send them anything we can think of to get the information across."

Only about half the 24 agency representatives interviewed in Cuyahoga County said that their agencies provide information about funding for services (186). With a few exceptions, the agencies that provide it furnish information pertaining only to funding for their own agency's services.

Only 1 of the 24 agency representatives was from an information and referral agency per se (186). The other 23 agencies do not provide information and referrals as a primary function but often provide information and referrals as a byproduct of intake for their own services—that is, if a person who contacts the agency is not eligible for the agency's services or needs services the agency does not provide, he or she is referred to another agency.

Other than the information and referral agency, most of the 24 agencies do not consider a person for whom they provide telephone information and referrals to be their client (186). Thus, a person does not become a "client" of the agency until he or she is linked to a service provided by the agency. Most of the 24 agency representatives said their agencies will provide information and referrals to anyone, even if the person needing assistance is not a "client" in this sense, but they seem to regard the information and referrals they provide for people they do not consider "clients" as an informal community service rather than a formal function of the agency.

The 24 agency representatives were asked what criteria their agency used to select a provider once the agency had determined that a person needed a particular service (186). The criteria named most frequently were the person's financial situation and the location of the service (8 mentions each). Other criteria mentioned were the provider's reputation and past performance (7 mentions); the patient's or family's needs, characteristics, and/or willingness to accept a provider (6 mentions); and the agency's informal affiliations with various providers (4 mentions).

Eighteen (75 percent) of the 24 agency representatives indicated that their agencies sometimes refer potential clients to other agencies for a service even though their own agency provides the service (186). Among the reasons for interagency referrals, geographic location was the most frequently cited. Other reasons included the referring agency's inability to accept new clients; patient or family preference; the patient's ineligibility for services from the referring agency (e.g., too young); agency rules or interagency agreements that certain categories of people (e.g., those in need of protective services) should be referred automatically to another agency; and financial considerations.

Some of the agency representatives said that clients are referred from one agency to another when third-party reimbursement for a client's care is no longer available to the first agency (186). They said that this practice is common when a client of a home care agency is hospitalized: when the person is discharged from the hospital, the hospital's home health care agency often provides care until third-party reimbursement runs out; then the person is referred back to the original agency for ongoing care.

One item of particular interest in this OTA assessment is how agencies that provide information and referrals for people with dementia keep current on what services are available. In the study in Cuyahoga County, OTA's contractors gave all of the 24 agency representatives a list of ways in which one might stay up-to-date and asked them which ways were used in their agency (186). The largest number of agency representatives (19 agencies or 79 percent) reported that their agencies use the Cleveland Alzheimer's Association Chapter to keep current on what services are available for people with dementia. (Interestingly, the perception of the staff of Cleveland Alzheimer's Association Chapter office is that very few agencies call the chapter for service information. Since the study in Cuyahoga County was conducted under the auspices of the Cleveland Alzheimer's Association Chapter, it is difficult to know how many agencies actually use the chapter to keep current and how many just gave the answer they thought the researchers wanted to hear.)

The majority of the 24 agency representatives interviewed in Cuyahoga County reported that their agencies use the countywide information and referral agency, local government offices on aging, Cleveland's Federation for Community Planning, and information supplied by other service providers to keep current on what services are available for people with dementia (186). Some of the agency representatives said that staff of their agencies keep current by attending health fairs, seminars, workshops, and committee and board meetings or through newsletters and published directories.

All 24 agency representatives reported that staff of their agencies use "informal friendships or association with other agency staff" to keep current on what services are available for people with dementia (186). On the basis of agency representatives' comments during the interviews, OTA's contractors concluded that informal networking is probably the primary way that agency staff members keep current on services for people with dementia. Staff members not only learn about specific services that way, but they also establish relationships with staff of other agencies that are invaluable later when they are trying to arrange services for a client.

All 24 agency representatives said their agencies initiate contacts with other service providers for at least some of the people for whom they provide information and referrals, but only 1 of the agencies initiates such contacts routinely (186). Other agencies encourage people to make their own contacts with agencies to which they are referred. Some agencies only initiate contact with other agencies if the person needing assistance is considered a client. Often, a decision about who should make the contact is based on staff judgment about the patient's or family's ability and willingness to make the contact. One of the 24 agency representatives referred to the process of agency-to-agency contact as "babying" people who are afraid of making their own contacts.

Finally, although most of the 24 agency representatives interviewed in Cuyahoga County said their agencies follow-up on some referrals to ensure that needed services are obtained, few agencies have systematic followup procedures. Some agencies ask the patient or family and the other provider to report back on the success or failure of a referral, but if these individuals do not report back, they are not contacted systematically by the agency.

Seven Reasons Why Accurate Information About Services and Funding for Services for People With Dementia Is Often Not Available

OTA's analysis of information and referral procedures and agencies in Cuyahoga County, Ohio, suggests that there are at least seven reasons why accurate information about services and funding for services for people with dementia is often not available. The seven reasons are highlighted in the discussion that follows. OTA's informal discussions with members of the advisory panel for this assessment and with numerous other people who work with dementia patients and their families in different communities suggest that the same reasons are applicable in many areas of the country beyond Cuyahoga County.

At the start of this assessment, OTA staff expected that the biggest problem families and others confront in trying to obtain accurate information about services and about funding for services for people with dementia would be the lack of information. In the course of the assessment, however, OTA found that *wrong information and partial information may be at least as big a problem as the lack of information*. Caregivers or others who contact an information and referral source and receive no information may continue to search for assistance from other information sources. People who receive wrong information—for example, those who are told, "There are no services," when, in fact, there are services—may just accept the information as correct and not even try to contact another source of information. Likewise, people who receive partial information—for example, those who are told, "There is an adult day care center 30 miles from here," when, in fact, there is another center much closer—may accept what they have been told, only to discover much later that there were other options. The origins of wrong and partial information about services and funding for services are identified in the following discussion.

1. **Because there are many potential providers of services for people with dementia and because the services they offer change from time to time, it is difficult for anyone to maintain an up-to-date list of available services.**

In the exploratory study in Cuyahoga County, Ohio, OTA's contractor sent a questionnaire to 324 agencies that they thought might provide information and referrals or services of any kind for people with dementia (186). Of the 97 agencies that completed survey questionnaires, 84 agencies said they did in fact provide information and referrals and/or services for people with dementia. It is likely, given the diverse needs of people with dementia and their caregivers, that a good number of the 227 agencies that did not respond to the survey are also potential sources of assistance. In addition, many voluntary associations and individual professionals to whom the questionnaire was not sent are potential service providers for people with dementia.

The fact that there are many potential service providers does not mean that enough services are available or that dementia patients' needs can be met. The study in Cuyahoga County did not address the many details about an agency's services that determine whether the services are really available to a particular patient and whether they meet his or her needs. Those details, which affect the availability of services from agencies in all parts of the country, not just Cuyahoga County, include:

- an agency's general eligibility criteria and any additional eligibility criteria for a specific service;
- the exact nature of the service;
- when and where the service is provided and for how long;
- what the service costs; and
- whether there is any source of funding for the service other than client fees.

These kinds of details often reflect regulations and requirements associated with the agency's funding source (e.g., Medicare, Medicaid, State programs). They may also reflect State or local government licensing or certification requirements and the mission, objectives, and history of the agency (391,481,641,821,831).

The details of an agency's services change from time to time, often in response to changes in the requirements of the agency's funding sources (641, 821,922). Federal, State, and local governments and private associations and foundations initiate new services and terminate others. Publicly and privately funded research and demonstration projects that provide services also begin and end. These changes may increase or decrease the availability of services. Since they also affect an agency's overall budget, these changes may also determine the total volume of services an agency can provide.

Some of the changes in agencies' services are small, but their cumulative impact is to create a constantly changing service environment. Agencies may continue to exist with the same name and in the same location, but the services they provide change in ways that make them more or less available, appropriate, accessible, and affordable for different kinds of people. Keeping track of all these changes in order to maintain an up-to-date list of available services is difficult and time-consuming. Yet such a list is an essential component of an effective system for linking people to appropriate services.

Home care services generally change more frequently and are more difficult to keep track of than nursing home services. Most patients and families prefer home care to nursing home care, however, and so it is important to keep lists of home care services up-to-date.

As awareness of Alzheimer's disease and other diseases that cause dementia has increased in recent years, new services designed specifically for people with dementia have been and continue to be developed in many communities. At the same time, research and demonstration projects established several years ago and other time-limited programs that provide services for some people are ending. Thus, the constant change that characterizes the service environment in general is probably even greater for services designed specifically for people with dementia.

Photo credit: N. Winter

To connect people with dementia to appropriate services, a linking system must have an accurate, up-to-date list of available services that includes all the kinds of services that may be needed for a person with dementia.

The number of potential service providers, the many details that determine whether their services are available and appropriate for a particular patient, and the constant change in services contribute to the difficulty families and others face in obtaining accurate information about services. It is easy to understand in this context why people sometimes receive wrong information or partial information about available services (324,641,821,939). The need for an accurate resource list and the difficulty of maintaining it are also clear.

Some areas of the country have fewer service providers than Cuyahoga County, Ohio, and some have more. In areas with fewer providers, maintaining an up-to-date resource list is less difficult but equally important for linking people to appropriate services.

In many communities, one or more agencies compile and update resource lists that may include all available services, certain types of services, or services for certain client groups. In some communities, the area agency on aging (AAA) or a local government office on aging maintains a list of services for elderly people. Lists compiled by these groups are not always complete or accurate with respect to services that may be needed for people with dementia, however. That observation is illustrated by the fact that in 1985, the Georgia Alzheimer's Disease Study Committee requested that the State's AAAs provide an inventory of services that might be used for people with dementia; the committee subsequently found that the inventories it received from the AAAs "varied widely in their completeness and accuracy to the extent that additional editing, followup, and refinement of responses [were] needed before they could be used" (246). Other State task forces and committees have not commented specifically on the completeness or accuracy of resource lists in their States, but some have noted that an accurate list is needed, and some have attempted to compile such a list, thus suggesting that the lists available to them were not adequate (37,142,360,396,497,500,538,599,713,790).

To maintain an accurate list of services requires a continuing commitment of resources. Computers and available software packages greatly facilitate the task, but whoever is maintaining the list must commit the time needed to keep track of changes, identify new services, and update the database. Government agencies and private groups sometimes pay for the development of a resource list on a one-time basis but fail to commit resources for updating it (259). As time passes, families and others that contact providers on the list find that some services have changed or are no longer available. New services may not be on the list at all. Without continual updating, the list itself can become a source of wrong or partial information.

2. **A large number of agencies and individuals provide information and referrals for people with dementia, but many of them do not have an accurate resource list or other effective methods for keeping up to date on available services.**

The study conducted for OTA in Cuyahoga County, Ohio, illustrates that a given area may have many sources of information and referrals for people with dementia (186). Of the 97 agencies that responded to the survey questionnaire that OTA's contractors sent to public and private agencies in the county, 75 indicated that they provide information and referrals for people with dementia. It is possible that some of the 227 agencies that did not respond to the survey also provide information and referrals. Furthermore, some of the voluntary associations and individual professionals who were not included in the agency survey may also provide information and referrals for people with dementia in Cuyahoga County.

From their interviews with 24 agency representatives in Cuyahoga County, OTA's contractors determined that, in general, agency staff keep up to date on available services through informal contacts and active networking—a process one agency representative called "hustle" (186). In the view of these contractors, the reliance of agency staff on informal contacts and relationships to keep current cannot be overstated. OTA's contractors found, however, that many of the agency representatives lacked a broad knowledge of available services, and the contractors concluded that although informal networking may be a valuable source of information about services, it is not sufficient by itself in a complex service environment, such as that found in Cuyahoga County and many other parts of the country.

To maintain an accurate list of services for people with dementia and their caregivers is difficult, as discussed earlier, and many agencies that provide information and referrals for people with dementia are unlikely to be able to commit sufficient staff time to maintain such a list. Individual physicians, other health care and social service professionals, and service providers who refer dementia patients and their families to services are also unlikely to be able to maintain an accurate resource list. A survey of 10 Alzheimer's Association chapters conducted for OTA in 1988 found that the chapters generally did not have systematic procedures for maintaining a comprehensive resource list (484).[7]

The large number of agencies and individuals that provide information and referrals for people with dementia, often without an accurate resource list, increases the likelihood that patients, families, and others will receive wrong information or partial information about available services. Given this problem, it would seem desirable to have a single agency in each community designated to maintain a list of available services and to allow other agencies and individuals easy access to the list. For such a system to function effectively, all agencies and individual service providers would have to be committed to it. Ideally, agencies and individual providers would share a database that they could access by telephone or through periodic receipt of updates on a magnetic storage medium (186).

3. **Many agencies do not track the people they serve by either diagnosis or condition and therefore do not identify people with dementia; people with dementia who are not identified as such are unlikely to receive appropriate information or referrals.**

People with dementia must be identified as such if they and/or their caregivers are to receive appropriate information and referrals. Very few of the agencies in Cuyahoga County that responded to the initial questionnaire or were interviewed keep records on the people they serve by either diagnosis or condition (186). Most of these agencies do not keep such records either on people for whom they provide telephone information and referrals or on people who receive services from the agency. A study of Massachusetts agencies that offer information and referrals and home care services found that these agencies also did not track the people they serve by either diagnosis or condition (756).

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[7] See ch. 8 for a discussion of the survey of 10 Alzheimer's Association chapters.

The fact that an agency does not track people it serves by their diagnosis or condition does not prove that the individual social worker, nurse, or other information and referral agent at the agency is unaware of the person's diagnosis or condition. It suggests that this could be the case, however. If a person with dementia is not identified as such by an information and referral agent, the person will not be referred for specialized services even if the services are available and appropriate for his or her needs. Furthermore, printed materials about dementia and caregiving techniques that could be helpful to the person's caregiver are unlikely to be provided; and common characteristics and care needs of people with dementia that influence the kinds of services they need may not be recognized.

It is important to note that some agencies do identify clients by their diagnosis or condition. Examples are Alzheimer's Association chapters, other voluntary associations that serve people with Alzheimer's, Huntington's, or Parkinson's diseases or stroke, and Alzheimer's diagnostic and assessment centers.[8]

4. The location of services is often an important factor in caregivers' decisions about service use, but agencies making referrals do not always consider location.

Many of the 26 caregivers of people with dementia who were interviewed by OTA's contractors in Cuyahoga County indicated that the location of a service influenced their decision about using the service (186). Many of the 24 agency representatives interviewed in Cuyahoga County also identified the location of services as a factor that affects use. For some patients and families, location is of concern because they do not have a car or other means of transportation. For others, location is of concern because there is a possibility that the person with dementia may become agitated on a long ride, and this prospect may discourage families from using services (488).

Some communities are so small that the location of services may not significantly affect caregivers' decisions about their use. In other communities, there is no choice of service providers because only one provider exists. In communities where there is a choice, however, it would be helpful to patients and caregivers if the referrals they got included the names of providers near their homes. Making such referrals requires the availability of a comprehensive resource list and may require special formatting of the list to identify providers in specific locations.

5. There are many potential sources of funding for services. Complex rules for each source make it difficult for anyone to provide accurate information about funding in general and even more difficult to provide information that is relevant to the service needs of a particular patient.

About half of the 97 agencies that responded to the initial survey questionnaire in Cuyahoga County indicated that they do provide information about funding for services, but the information that most of them provide pertains only to funding for their own agency's services (186). Few of the agencies responding to the survey indicated that they offer benefits counseling (i.e., information about various sources of funding for services and how and where to apply for benefits).

The OTA contractors who conducted the study in Cuyahoga County concluded that benefits counseling is difficult to provide (186). One of the reasons it is difficult is that there are many potential sources of funding for services. Many Federal, State, and local government programs, private agencies, and voluntary and charitable organizations pay for some services that may be needed for people with dementia. Furthermore, some people have private insurance that covers some services.

It is important to emphasize that the fact that there are many potential sources of funding for services does not mean that adequate funding is available. Each funding source has rules that limit the availability of funds by restricting who is eligible and what services are covered. Eligibility may be restricted on the basis of a person's age, income, assets, diagnosis, physical or mental condition, residence, family composition, and other factors. Coverage may be restricted by rules about the type of service that can be paid for; the profession, training, and licensure of a person who can be reimbursed for providing the service; the setting in which it can be provided, and its duration and frequency (124,391,641,831). The rules in each of these areas are interrelated, so that a particular service is paid for only if it is provided to a patient with a certain diagnosis or condition, by a certain provider, in a certain setting, for a given time period.

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[8] Regional Alzheimer's diagnostic and assessment centers are discussed in ch. 8.

It is often unclear whether a person with dementia will be eligible for services paid for by certain programs—especially programs like Medicare and Medicaid that have eligibility and coverage requirements related to a person's physical condition and physical care needs. Although many people with dementia are determined to be ineligible for funding for services through these programs (124,186,831), other people with dementia do receive services paid for by these programs. This situation may arise because of real differences in the physical condition and physical care needs of different patients. On the other hand, it may arise because of differences in the way a patient's condition and care needs are described on an application or billing form or because of different interpretations of a program's regulations by its administrators. The eligibility and coverage requirements for services paid for or provided by the U.S. Department of Veterans Affairs (VA) are particularly complex and difficult for non-VA information and referral sources to understand or explain to caregivers.[9]

To further complicate an already confusing situation, the eligibility and coverage requirements of all funding sources change from time to time. Overall funding levels also change, and so the total amount of available assistance varies over time.

The large number of potential sources of funding for services, the complexity of their eligibility and coverage requirements, changes in the rules and overall funding levels, and uncertainty about whether a person with dementia fits within the eligibility and coverage requirements make it extremely difficult for anyone to provide accurate information about available funding (186,641,790). It is easy to understand in this context why families and others receive wrong, partial, or no information about potentially beneficial funding sources.

United Seniors Health Cooperative, a nonprofit organization in Washington, DC, has developed a computerized service that identifies an elderly person's potential eligibility for more than 50 local, State, and Federal funding programs (799). This service, called the "Benefits Outreach and Screening Service," is a promising approach to making available accurate information about funding for services. To use the Benefits Outreach and Screening Service, an individual completes a questionnaire about his or her finances, medical condition, and other information. That information is then fed into a computer, which reviews the available funding programs, identifies benefits the person may be eligible for, and prints out a list of those benefits and instructions on how and where to apply for them. The software package for the service has been purchased by a consortium of human service agencies in Buffalo, New York, and by agencies in 15 other areas of the country, including AAAs in Virginia and county government agencies in Wisconsin. As of late 1989, the software was being adapted for use in New York State, where it will not only identify benefits the person may be eligible for but also print out completed applications for six publicly funded programs (799).

6. **The terms used for many services that may be needed for people with dementia are new to families and others. If families and other caregivers do not understand what the services are, information about the availability of these services is meaningless to them.**

For various reasons, the terms used for many services that could benefit people with dementia may not be understood by families and others (324). Terms such as "respite care," "congregate meals," "case management," and "telephone reassurance" are new to many families. Interestingly, OTA's contractors in Cuyahoga County found that even some caregivers who had used case management did not recognize the term (186).

The terms used for some services reflect the requirements of their funding source, and not necessarily the needs of patients or the actual services provided. Examples are "homemaker" and "home health aide" (299,303). Medicare pays for "home health aides" in certain circumstances but rarely pays for "homemakers;" the difference between the two is defined in Medicare regulations. Many caregivers who need someone to help them take care of a dementia patient at home are not familiar with the Medicare regulations and do not define their service needs in terms of those regulations. Such caregivers are not likely to understand the difference between a "homemaker" and a "home health aide" without a clear explanation, and as illustrated in the case of Mrs. D in chapter 1, some service providers have difficulty explaining the difference clearly. The biggest difference often is who pays for the service, not what is provided.

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[9] The complexity of the VA's eligibility and coverage requirements is described in ch. 6.

Information and referral agencies often categorize services according to the terms providers use for the service. If someone calls an information and referral agency for information about a service but uses a different term for it than the provider uses, the person may not be told about a potentially helpful provider. Instead, the person may be told about providers who call their service what the person said he or she wants but may not offer what the person actually needs.

Information about services is meaningless to families and others who do not understand what the services are. To make the information meaningful, the service must be described and categorized in terms relevant to patients' and caregivers' needs. Categorizing services in a way that is relevant to the needs of patients and families, however, is a difficult task for information and referral agencies (183).

7. **Proprietary concerns and agency turf issues sometimes deter staff in one agency from giving people information about another agency's services.**

Although nearly 75 percent of the 24 agency representatives interviewed in Cuyahoga County said their agencies sometimes refer people to other agencies for a service even if their own agency provides it, OTA's contractors concluded that most of the agencies refer people to their own services (186). This practice is to be expected because the staff of a particular agency are most familiar with their own agency's services and because the services of one's own agency are often easiest to arrange. On the other hand, referring a patient to the services of an agency other than one's own may be more appropriate if the other agency is closer to the patient's home or offers services that are more appropriate for the patient's needs.

To say that proprietary concerns deter one agency's staff from giving people information about another agency's services implies that the first agency is aware of the other agency's services, knows they are appropriate for the patient, and still does not refer the patient or family to that agency. That was the implication in some agency representatives' complaints about hospitals that provide home care for patients through their own home health care agency until the patients' third-party reimbursement runs out and then refer the patients to another home care agency (186).

A different problem occurs when one agency's staff members do not give people information about another agency's services because they are not aware of the other agency's services or do not consider those services appropriate for a patient's needs. This situation is particularly likely to occur when the two agencies are in different "systems."

As discussed in chapter 1, most services for people with dementia are provided in one of several broad systems: the medical care system, the aging services system, the mental health system, the social service system, the public health system, and the public assistance system. These systems are delineated by the Federal programs that fund them, the training of people who work in them, and historical divisions among State and local government agencies that administer the services. Although not rigidly differentiated, the systems generally are not integrated with one another.

For several reasons, referrals are more likely to occur within a system than from one system to another. One reason is that informal networking between agencies often occurs only within a given system, and service providers in one system may not be aware of services in other systems. Another reason is that service providers in the same system tend to have a common perspective on dementia and the appropriate care for people with dementia. Thus, they may have greater understanding of and confidence in services provided by other agencies and individuals in their system than in services provided by other systems. Consequently, agencies in one system, say the mental health or social service system, may not refer people to services provided by agencies in another system, say the aging services system; and conversely, agencies in the aging services system may not refer people to services provided in the mental health or social service systems.

Proprietary concerns and agency turf issues sometimes interfere with the development of an accurate list of available services. A list developed by someone in one system may not include services provided by agencies in other systems. In addition, anecdotal evidence suggests that some agencies do not want an accurate list to be developed because they are afraid they will lose clients to other agencies (611).

At the time of the study in Cuyahoga County, proprietary agencies were not included in the resource list of the countywide information and referral agency (185). OTA does not know whether proprietary and nonproprietary agencies constitute separate systems in other areas of the country. Clearly, beneficial services for persons with dementia are provided by both proprietary and nonproprietary agencies, and caregivers and others need to know about services provided by both types of agencies in order to make informed decisions about the patient's care.

The first steps in overcoming turf problems that interfere with the availability of accurate information about services are to include all providers in the resource list and to foster a sense of joint ownership of the list. As discussed elsewhere in this report, there is a general need for integration of services, service providers, and systems.

Implications for an Effective System To Link People With Dementia to Services

Given the large number of potential services, service providers, and sources of funding and the complex and changing rules that restrict their availability, it is not surprising that families and others sometimes receive wrong, partial, or no information about services and funding for services for people with dementia. The many agencies and individuals that provide information and referrals for people with dementia compound the potential for error. Although some agency staff members, individual health care and social service professionals, and service providers are undoubtedly more knowledgeable about available services than others, families and others who need help in locating appropriate services have no way to tell the difference.

The discussion in this section has turned repeatedly to the importance of an accurate, comprehensive resource list. Without such a list, agency staff, individual health care and social service professionals, service providers, voluntary associations, and others that refer patients and families to services must rely on informal networking and "hustle" to keep current on available services. These methods are helpful, but they are not sufficient in complex service environments.

Most areas of the country have fewer agencies and individual service providers than Cuyahoga County, Ohio, and some communities may have so few that a formal resource list is not necessary. In the course of this assessment, however, OTA has been told by many individuals that there are no services in a given community, but later has been told by other sources that there are some services, either in that community or readily available to its residents from a nearby community. This situation has occurred most often when, for example, the available services are provided by a mental health agency and the individual is familiar with social service or aging network agencies. OTA does not intend to suggest here that sufficient services are available if all systems are considered, but only to point out that even people who are concerned about services for people with dementia and think they know what is available in their community may not be aware of some services.

Maintaining an accurate resource list is difficult and requires a continuing commitment of resources. Ideally, one agency in a community should maintain the list and other agencies and individuals should have access to it. To address caregivers' concerns about the location of services, lists for other than very small communities should be formatted to allow easy retrieval of information about service providers in a given geographic area. To begin to address some of the turf problems that interfere with the availability of accurate information about services, the list should include all service providers and be readily available for their use.

Computers make it easier now than in the past for an agency to compile and update a resource list and to make the updated version of the list available to other agencies and individual service providers. Special computer software, such as that used for the previously described Benefits Outreach and Screening Service created by United Seniors Health Cooperative (799), may be the only effective way to keep track of the large number of funding sources and the complex and changing eligibility and coverage requirements that determine whether benefits are available to an individual.

The availability of an accurate and comprehensive resource list would neither change the inherent complexity of the service environment at the community level nor make up for lack of services. It would improve access, however, and, by letting people know what services exist, it would allow for more appropriate use of services. Likewise, the availability of accurate information about funding for services would neither change the inherent complexity and fragmentation of public and private programs that pay for services nor make more funding available. It would increase the likelihood that people receive benefits for which they are eligible, and it would allow families and others to plan realistically for the care of people with dementia. The process of compiling and maintaining an accurate resource list also could aid in efforts to identify gaps in services and funding for services for people with dementia.

If a single agency in a community were designated to maintain an accurate resource list, the designated agency would not have to be the source of all referrals or the single access point for services. The desirability of establishing a single access point for services in each community has been debated by many investigators (see, e.g., Callahan, 1981 (104), and Piktialis and Callahan, 1986 (661)). Some service providers fear that if a single agency is designated to maintain the resource list, that agency will control referrals and may discriminate against certain providers (611). If the single agency were required to make the resource list widely available, however, other agencies, individual health care and social service professionals, voluntary associations, and others could use it themselves to make referrals.

The findings from Cuyahoga County, Ohio, and elsewhere suggest that people with dementia are not always identified as such by agencies that provide information and referrals (186,756). In the past decade, the awareness of Alzheimer's and other dementias has increased greatly among health care and social service professionals and service providers. Nevertheless, some people who provide information and referrals are not trained or predisposed to identify dementia in their clients. A system to link people with dementia to services must include mechanisms for identifying people with dementia if it is to provide appropriate information to such people or refer them to appropriate services.

Lastly, OTA's contractors found that most of the agencies that responded to the survey in Cuyahoga County do not have systematic procedures to follow-up on referrals to make sure patients receive needed services (186). The lack of followup procedures does not pertain to the availability of accurate information about services, the topic of this section, but it is relevant to a different question: If accurate information about services for people with dementia is available, can patients, families, and others use it to locate and arrange the services they need? That question is touched on in the following section and discussed in detail in chapter 3. OTA's contractors in Cuyahoga County noted a difference between the kind of referral support, including followup, received by people who are considered clients of an agency and the referral support received by people who just get information and referrals over the telephone (186). Patients and families who need assistance to follow through on a referral are more likely to receive it if they are considered clients of the referring agency. In either case, however, without systematic followup procedures, an agency that provides information and referrals is unlikely even to know which of the people it has referred to services actually needed more help to follow through on the referrals. Systematic follow-up procedures are essential to keep such people from "falling through the cracks."

WHAT IS SPECIAL ABOUT THE INFORMATION AND REFERRAL NEEDS OF PEOPLE WITH DEMENTIA

Many aspects of the information and referral process are similar for individuals with dementia and individuals with other conditions, but there are some differences that are relevant to developing an effective system to link people with dementia to services. Several of these differences are identified in the following discussion, which draws on the observations of administrators of State information and referral programs, an analysis of data on callers to the "Home Help Line" of the Benjamin Rose Institute in Cleveland, and some findings from the caregiver interviews that were part of the study conducted for OTA in Cuyahoga County, Ohio.

Comments by Administrators of State Information and Referral Programs

Comments to OTA by the administrators of some State information and referral programs suggest that calls made about services for people with dementia often require more time than calls about services for other people. The director of Alzheimer's Information Services in Massachusetts, for example, has told OTA that calls received by the State's Alzheimer's telephone information and referral program usually last much longer than calls received by the State's general information and referral program for elderly people (121). He estimates that whereas calls to the State's general information and referral program for elderly people usually last only a few minutes, calls to the Alzheimer's information and referral program typically last about 20 minutes and sometimes last as long as an hour and a half.

An administrator in the Oklahoma Special Unit on Aging that has a telephone information and referral program for elderly people has told OTA that people who call the program for a person with dementia usually want more than information and referrals (544). He says that people calling for a person with dementia are much more likely than people calling for a nondemented elderly person to "want to talk."

The director of the North Carolina Alzheimer's telephone information and referral program also says that people who call that program often want more than information and referrals (290). Her perception is that many callers want help in understanding dementia and defining the patient's service needs, as well as information and referrals.

An Analysis of Data on Callers to the Benjamin Rose Institute's Telephone Information and Referral Program

OTA is not aware of any research that specifically compares the process of information and referral for people with dementia to the process for nondemented people. In the absence of such research, the OTA contractors who performed the study in Cuyahoga County, Ohio, analyzed data that was collected in 1984 and 1985 on people who had called the Benjamin Rose Institute's telephone information and referral "Home Help Line" in those years (186). The Benjamin Rose Institute is a nonprofit agency in Cleveland, Ohio, that conducts research and provides health care, social services, and residential care for elderly people.

OTA's contractors compared data on two groups of people who had called Benjamin Rose Institute's Home Help Line:

- 30 individuals who had called the Home Help Line for an elderly person with a mental impairment (e.g., Alzheimer's disease, mental illness, brain damage, forgetfulness, confusion, or senility[10]); and
- 116 individuals who had called the Home Help Line for an elderly person with a physical health condition and no mental impairment (186).

OTA's contractors found several differences between the two groups of callers that point to special aspects of the information and referral process for people with dementia (186). First, more than one-third (36 percent) of the physically impaired people called the Home Help Line themselves, but none of the mentally impaired people did. This finding illustrates the limited capacity of people with a mental impairments to contact an information and referral source for themselves and supports the conclusion of this OTA assessment that an information and referral program is not itself sufficient to link people with dementia to services; as discussed in chapter 3, people with dementia who have no family member or other informal caregiver to help them may require outreach and case management.[11]

People who had called the Home Help Line for a mentally impaired person were more likely than people who had called for a physically impaired person to have previously contacted another agency that could not provide the needed assistance. The two groups of callers also differed in their reasons for calling the Home Help Line. People who had called for a mentally impaired person were more likely than people who had called for a physically impaired person to say:

- that they needed help in deciding what types of services would be most helpful;
- that they needed to know what services Medicare and Medicaid cover; and

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[10] The definition of mental impairment in the Benjamin Rose Institute's data set included mental illness as well as dementia, so the findings do not pertain only to people with dementia.

[11] For OTA's analysis in support of this conclusion, see ch. 3.

- that they needed help in knowing what tasks they could expect someone they hired to do (186).

Another difference between the two groups was in the percentage of people in each group who made it through various steps in the process of getting services. OTA's contractors identified five steps in that process:

1. contacting an information source to obtain a referral;
2. receiving the name of a service provider;
3. contacting the provider;
4. finding that the provider actually offers the needed service; and
5. using the service (186).

When OTA's contractors compared people who had called the Home Help Line for a mentally impaired person and people who had called for a physically impaired person in relation to these steps, they found two differences (186). First, the percentage of people who received a referral was smaller for people who had called for a mentally impaired person (79 percent) than for people who had called for a physically impaired person (86 percent). Second, the percentage of people who ended up using the service to which they were referred was smaller among the mentally impaired people (11 percent) than among the physically impaired people (19 percent).

OTA's contractors also found that the people who had called the Home Help Line for a mentally impaired person were more likely than people who had called for a physically impaired person to say that they were having difficulty providing care (e.g., were not able to continue giving the same amount of assistance they had been giving or did not have enough time or energy to provide the care needed) (186). Research indicates that the caregivers of cognitively impaired people are generally more stressed than caregivers of physically impaired people (161,296,415,612). The finding that people who called the Home Help Line for a mentally impaired person were more likely to have problems providing care suggests that providers of information and referral for people with dementia must be especially attentive to the needs of caregivers.

Findings From Interviews With Caregivers in Cuyahoga County, Ohio

As noted earlier, the OTA-commissioned study in Cuyahoga County, Ohio, included interviews with 26 caregivers who called the Cleveland Alzheimer's Association Chapter's telephone helpline between April and July 1988 (186). Many of the 26 caregivers said they had been unsure at the time they called the helpline about what service they needed, and half of them said they had called the helpline for assistance in deciding what types of services would be most helpful. Six caregivers (23 percent) said they had called to find out what services Medicare or Medicaid cover. Several caregivers said they had called the Alzheimer's helpline just to talk, and many seemed to be reaching out for emotional support and reassurance.

Eleven (42 percent) of the 26 caregivers had previously contacted other agencies, including information and referral agencies, diagnostic centers, social service agencies, hospitals, and nursing homes. One spouse who was looking for day care said, "I was not able to find anything out." A daughter said she had called hospitals and other agencies and that her call to the helpline was motivated by "complete frustration." Another daughter said, "I called numbers from the telephone book—it was a waste of time."

Although not all of the 26 caregivers had called the Alzheimer's helpline for a referral, 23 caregivers received the name of one or more service providers (186). Of these 23 caregivers, almost half (11 caregivers) did not subsequently contact the service provider(s) recommended. The caregivers who did not contact the recommended service provider(s) gave a variety of reasons. Two of them cited the anticipated cost of the service; a third decided she did not need the service yet; and a fourth said she did not contact the recommended provider because "the phones at the agencies were not answered or the line was busy." In one case, a granddaughter had received referrals for day care and nursing homes for her grandmother, but her parents were not willing to act on the recommendations she received. In another case, a son caring for his 83-year-old mother felt that the referral he received did not go far enough: "I was told to find a doctor on my own and was sent a list of hospitals. I didn't contact any of them because no one recommended a specific doctor."

Of the 12 caregivers who did contact the recommended service provider(s), 9 caregivers reported that the provider(s) actually offered the needed service, and all 9 used the service (186). The other three caregivers who contacted the recommended service provider found that the provider did not have the service they needed. Two of the three said the hours that services were offered by the provider did not meet their needs. The third caregiver who was caring for her mother who had both dementia and cancer felt that no agency she contacted provided the kind of care her mother needed.

The percentage of caregivers who advanced through the five steps in the process of getting services and actually used the service(s) to which they were referred was larger among the caregivers who got a referral from the Cleveland Alzheimer's Association Chapter's helpline (35 percent) than among people who contacted the Benjamin Rose Institute's Home Help Line (11 percent) (186). Although the reasons for this difference are unclear, it may be attributable to one or more of the following factors: 1) as a helpline operated by a dementia-specific organization, the helpline operated by the Cleveland Alzheimer's Association Chapter may attract callers with more clearly defined needs than the Home Help Line of the Benjamin Rose Institute; 2) caregivers who contact the Alzheimer's Association helpline may be in more immediate need of services than caregivers who call the Benjamin Rose Institute; 3) the person who staffs the Alzheimer's Association helpline may provide comparatively more support to callers, thus encouraging them to follow through on referrals; 4) the service providers to which Alzheimer's Association helpline callers are referred may be more appropriate for the needs of people with dementia; or 5) the callers to the Alzheimer's Association's helpline may regard the helpline as a source of expertise about the special needs of a person with dementia, thus adding to the credibility of the referral.

Implications for an Effective System To Link People With Dementia to Services

The preceding discussion of special aspects of the information and referral process for people with dementia suggests that the information and referral component of a system to link people with dementia to services must meet certain requirements in order to function effectively. In particular, the staff of the information and referral program must be able to spend enough time to understand the individual caregiving situation and to help the caregiver define the patient's care needs and determine what types of services would be helpful. In addition, the staff must be:

- knowledgeable about dementia and the care needs of people with dementia;
- knowledgeable about services for people with dementia;
- able to provide accurate information about eligibility and coverage for services that may be needed for people with dementia through Medicare, Medicaid, and other funding sources; and
- attuned to the stresses associated with caring for a person with dementia and the difficulties dementia caregivers may have already encountered in trying to obtain accurate information about services and funding for services.

These requirements define what it would mean for an information and referral program to be *dementia-capable*. Some people believe that only a dementia-specific information and referral program, i.e., a program that serves only people with dementia and their caregivers, could meet the requirements. Most of the members of the advisory panel for this OTA assessment concluded that an information and referral program that serves other elderly and disabled people as well as people with dementia could meet the requirements, but only with explicit recognition of the special information and referral needs of people with dementia, a commitment to serve such people, and special training for the staff.

WHAT IS SPECIAL ABOUT THE INFORMATION AND REFERRAL NEEDS OF ETHNIC MINORITY PEOPLE WITH DEMENTIA

Ethnic minority people with dementia and their families face all the same problems in obtaining accurate information about services and about funding for services as other people, but they also face additional problems due to language and cultural differences and demographic factors. At the start of this assessment, OTA could not find any research on information needs or information and referral procedures for ethnic minority people with dementia. Several studies of ethnic minority people in general have found that lack of information interferes with their use of services (see, e.g., Guttman, 1980 (284); and Holmes, et al., 1979 (329)). On the other hand, a telephone survey of 1,608 black, Puerto Rican, Mexican-American, and other white people found little difference among three of these groups (blacks, Mexican-Americans, and other whites) in their knowledge about services and funding for services (330). Only the Puerto Rican group was significantly less likely to know about services and funding for services.

In 1988, to determine how ethnic minority people with dementia are linked to services and to identify any special problems that may arise in the linking process for them, OTA commissioned an exploratory study in California (866). That study is described in the next section and its implications for an effective system to link ethnic minority people with dementia to services are discussed.

Findings From a Study of Four Ethnic Minority Groups in Two California Counties

The OTA-commissioned study of how ethnic minority people with dementia are linked to services was conducted in two counties in California (Los Angeles and San Diego Counties) (866). OTA's contractors conducted interviews with families and other informal caregivers of black, Hispanic, Japanese, and American Indian people with dementia and with staff members of agencies that provide services for people in the four ethnic groups. After they compiled the results of the interviews, the contractors and OTA staff met with some of the interviewers and service providers from three of the four groups—blacks, Hispanics, and Japanese—in order to discuss the findings and their policy implications. Unfortunately, they were unable to arrange a meeting with the American Indian service providers in the time available for the the study.

Several limitations of the study in California should be noted. First, the study sample does not represent all ethnic minority groups. OTA's contractors had hoped to include Chinese and Korean caregivers to broaden the Asian-American sample, but the necessary interviews could not be arranged. Many other groups also could have been included, since there are more than 100 ethnic groups in the United States (491,792). Second, even for the groups that were studied, the sample is not representative. People with dementia who have no informal caregiver were not included in the study, for example. Lastly, the sample is composed largely of patients and caregivers who were successfully linked to services. Patients and caregivers who are not receiving services are underrepresented (866). Thus, the findings of the study in California depict a "best case scenario" with respect to linking ethnic minority people with dementia to services. The study did identify many problems, though, and it provides useful insights into the information needs of ethnic minority people with dementia and their caregivers. To OTA's knowledge, it is the only source of data on this topic.

OTA's contractors interviewed 88 ethnic minority caregivers, including 35 blacks, 25 Hispanics, 18 Japanese, and 10 American Indians (866). The study questionnaires were translated into Spanish and Japanese, and the interviewers for the Hispanic and Japanese caregivers were bilingual. Even though most of those caregivers were bilingual, they generally preferred to be interviewed in their native language. The black and American Indian caregivers were interviewed in English.

As shown in table 2-4, when asked if they knew about specific services, the majority of the ethnic minority caregivers said they knew about the following services: diagnosis and other physicians' services, transportation, home health care, home-delivered meals, nursing homes, chore services, information and referral, financial counseling, and mental health services (866). Less than half of the caregivers said they knew about adult day care, paid companion, protective services, and legal services. The results of in-depth interviews with the caregivers indicate that these responses reflect service consciousness (i.e., general awareness of services) rather than service knowledge (i.e., knowledge of a specific provider in the community) (865).

OTA's contractors found considerable variation among the four ethnic groups with respect to the percentage of caregivers who said they knew about each service (866). Some of the variation may have been due to differences in the types of services provided by the agencies from which the individuals were receiving services. Quite possibly caregivers know more about services of agencies to which they are connected than about services of other agencies. Moreover, some services are more readily available to some groups than to others.

Table 2-4—The Percentage of Ethnic Minority Caregivers Who Said They Know About Certain Services, Los Angeles and San Diego Counties, California, 1988

Service	Total sample (N = 88)	Blacks (N = 35)	Hispanics (N = 25)	Japanese (N = 18)	American Indian (N = 10)
Physicians' services	85%	74%	100%	89%	89%
Diagnosis	64	71	96	33	56
Transportation	80	66	100	72	90
Home health care	77	66	88	78	90
Home-delivered meals	77	63	92	78	90
Nursing home	68	77	100	95	90
Chore services	67	77	84	50	20
Financial counseling	63	43	80	77	78
Information & referral	60	45	64	61	56
Mental health services	55	34	76	61	60
Adult day services	41	26	44	56	60
Paid companion	39	20	68	39	33
Protective services	38	34	56	28	22
Legal services	36	17	52	44	56

SOURCE: R. Valle, L. Birba, J. Yeider, et al., "Linking of Ethnic Minority Elderly With Dementia to Long-Term Care Services," contract report prepared for the Office of Technology Assessment, U.S. Congress, Washington DC, 1989.

Many of the ethnic minority caregivers interviewed by OTA's contractors said they needed each of the services mentioned (866). The caregivers were asked in this context how they would find out about and arrange a service they needed. Surprisingly, in this sample of caregivers, most of whom were connected to agencies already, only 17 of the 88 caregivers (19 percent) said they would contact an agency for assistance in locating and arranging the service. Most of the other caregivers said they would try to find out about and arrange the service themselves or ask a family member for help in locating and arranging the service. Some caregivers did not answer the question, thus suggesting that they did not know how they would find out about or arrange the services they needed.

The interviewers concluded that although most of the 88 ethnic minority caregivers were linked to an agency already, they had no concept of a process by which they might obtain help in locating and arranging services (866). Even caregivers who reported knowing about information and referral programs (60 percent of the sample) said they would turn internally to themselves or their families for help in locating and arranging services. The interviewers came away with the impression that these apparently "connected" caregivers were still quite isolated from formal sources of help.

OTA's contractors interviewed 48 individuals who provide services for the 4 ethnic minority groups in the two California counties: 19 black service providers, 8 Hispanic service providers, 7 Japanese service providers, 7 American Indian providers; and 7 other white service providers (866). Sixty-six percent of the 48 service providers had worked for at least 3 years with ethnic minority people with dementia.

The service providers interviewed by OTA's contractors said that many ethnic minority caregivers in their areas have very little knowledge about dementia (866). The service providers also said that with some exceptions, knowledge about dementia is quite limited among the staff of agencies that serve ethnic minority people in the areas studied. Among the 48 service providers who were interviewed by OTA's contractors, 55 percent rated their own knowledge about dementia as moderate, while 40 percent rated their knowledge as high and 6 percent rated their knowledge as low.

The service providers who were interviewed said that dementia frequently is not identified in ethnic minority people for a variety of reasons:

- because families regard patients' cognitive deficits and behavioral problems, if any, as part of normal aging;
- because families feel there is a stigma attached to some symptoms of dementia and hide the patients; and/or
- because health care and social service professionals and service providers who interact with patients are not trained to identify dementia (866).

On the other hand, most of the ethnic minority caregivers interviewed for the study said the person they were caring for had been formally evaluated and diagnosed as having dementia (866). This included 40 percent of the American Indian patients, 60 percent of the black patients, 56 percent of the Japanese patients, and 84 percent of the Hispanic patients. The service providers considered these percentages unusually high for the communities.

The overall impression of the interviewers and OTA's contractors was that the problem of dementia is only one of many problems facing service providers in ethnic minority communities. Available resources are stretched thin, and agencies are overwhelmed by many urgent needs. Understandably, many service providers regard dementia as just one more problem to handle with limited funds and staff capability. In fact, some service providers seemed to regard the available resources for the care of people with dementia as so limited that there was no practical reason for identifying dementia in their frail elderly clients.

Implications for an Effective System To Link Ethnic Minority People With Dementia to Services

The interviews with ethnic minority caregivers and service providers in the OTA-commissioned study in California (866) and the interviewers' comments in meetings with OTA staff suggest four areas of consensus about special information needs and information and referral procedures for ethnic minority persons with dementia and their caregivers. Those four points are discussed below.

1. **Information about dementia and about services for people with dementia should be available in the native language of patients and caregivers.**

As noted earlier, the Hispanic and Japanese caregivers interviewed in the California study were bilingual but they generally preferred to be interviewed in their native language. Many of the people they were caring for spoke Spanish or Japanese exclusively. It was the consensus of the interviewers, service providers, and OTA's contractors that these patients and caregivers and others like them would have much greater difficulty understanding information about services and about funding for services or would be completely unable to understand the information if it were in English rather than in Spanish or Japanese.

An example of the differential impact of information presented in English v. the caregivers' native language occurred in the fall of 1988, at the Little Tokyo Service Center, an agency in Los Angeles that provides services for Japanese people of all ages. Concerned about Japanese caregivers' lack of knowledge about dementia, a social worker at the Little Tokyo Center arranged two informational meetings for caregivers, a week apart, one to be conducted in English and one in Japanese. For both meetings, the main speaker was a Japanese neurologist who is well known in the community. Whereas 10 people attended the meeting conducted in English, 60 attended the meeting conducted in Japanese. During the latter meeting, several caregivers expressed strong interest in setting up a support group for caregivers. The same interest was not expressed in the other meeting (739).

One Hispanic interviewer told OTA about caregivers she interviewed who had gone to a local government agency to apply for public assistance and medical assistance and did not understand why they had been turned down. The interviewer's opinion was that even though the caregivers spoke and understood some English, they did not do so well enough to understand the complex eligibility requirements for these publicly funded programs. Her impression was that the families were very poor and probably eligible for assistance, so she suggested that they appeal. They did not do so, she said, because they did not think they could speak English well enough to present their case effectively to the agency staff (262).

The Los Angeles County Department of Social Services has an Asian unit with case workers who speak Japanese, Chinese, Korean, and Vietnamese to process applications for public assistance and medical assistance (739). OTA does not know whether there is a similar unit with Spanish-speaking case workers, but the department does have Spanish-speaking case workers in some offices (865).

While visiting agencies for the study in California, OTA's contractors noted a lack of printed materials in languages other than English about Alzheimer's disease, dementia, and services for people with dementia—a lack which contrasted with an extensive array of non-English-language printed materials on other health and mental health problems. In the opinion of OTA's contractors, the lack of non-English-language printed information about dementia is one of the biggest problems preventing access of ethnic minority people with dementia to appropriate services (866).

The Alzheimer's Association has recently translated some of its brochures into Spanish and is distributing them. The social worker at the Little Tokyo Service Center, frustrated by the lack of any information about Alzheimer's disease in Japanese, translated an Alzheimer's Association pamphlet herself in the fall of 1988 (739). Translating these materials into many different languages and promptly distributing the products would appear to be both an achievable objective and a minimum requirement for linking ethnic minority people with dementia and their caregivers to services.

It is not known how many ethnic minority people with dementia or their caregivers need information in a language other than English. Elderly people are more likely than younger people to use their native language (862). Since most patients and many caregivers are elderly, the need for information in other languages may be widespread. In fact, Census Bureau data indicate that among elderly people who speak Japanese at home, 53 percent do not speak English well or do not speak it at all. Likewise, among elderly people who speak Spanish at home, 61 percent do not speak English well or do not speak it at all (863).

2. Information about dementia and about services for people with dementia must be culturally appropriate.

The cultural heritage, traditions, customs, and beliefs of an ethnic group affect how and when members of the group perceive the problem of dementia, who is expected to be the caregiver, what that person's responsibilities are, whether formal services are acceptable, and how and when they are sought (160,315,864). All these factors are relevant to the information needs of ethnic minority people with dementia and their caregivers. In particular, these factors influence what information about dementia, services, and service providers is meaningful and appropriate for them.

It has been suggested, for example, that memory loss and other cognitive deficits associated with dementia are noticed sooner by and are more troublesome to groups that place high value on cognitive and intellectual functions than to groups that place high value on affective or emotional functions. The latter groups are more likely to be troubled by personality changes associated with dementia or by the failure of the demented person to fulfill his or her accustomed role in the family (237). If information about dementia is to be meaningful to ethnic minority people, it must focus on the aspects of the problem that are troublesome to them. The text of pamphlets and other informational materials should reflect these differences (863).

Cultural factors also are relevant in selecting appropriate service providers for ethnic minority people with dementia. Many of the ethnic minority caregivers interviewed for the study in California were using services from agencies that primarily serve one ethnic minority group (866). Staff of these agencies often are members of the same ethnic group, and the services are adapted in various ways to that group's customs and values.

The ethnic minority service providers who were interviewed in California emphasized the importance of the cultural appropriateness of services (866). Sixty-six percent of the 48 service providers interviewed said that in their experience, an agency's failure to respond to cultural values and concerns was a common barrier to the use of the agency's services by ethnic minority people. In order to refer patients and families to appropriate service providers, an information and referral agent must be aware of their cultural background and knowledgeable about agencies' and individual providers' capacity to serve people of different cultural backgrounds.

3. Information about dementia and about services for people with dementia must be tailored to demographic differences among and within ethnic minority groups.

Demographic factors, such as income and educational background, vary both among and within ethnic minority groups. Although the four ethnic minority groups studied by OTA have lower average incomes than the majority population, not all ethnic minority people have low incomes. The same is true for educational background. Whereas cultural factors are specific to a particular ethnic group, demographic factors cut across ethnic groups (866). The combination of language and cultural differences among ethnic groups and demographic differences among and within ethnic groups creates a complicated mix of information needs.

Ethnic minority people in groups that have relatively low incomes are likely to be eligible for means-tested services and benefits (492,455). Accurate information about these services and benefits is clearly important for them. On the other hand, information and referral agents cannot assume that individual ethnic minority people have low incomes or that they have a special need for information about means-tested programs.

The educational background of patients and families is relevant to the content, "pitch," and format of printed information about dementia and services for people with dementia (866). Public education messages for radio, television, and other nonprint media also must take into account the formal educational background of the intended audience. OTA's contractors found that educational background varied greatly both among and within the four groups of ethnic minority caregivers interviewed in San Diego and Los Angeles Counties.

To create informational materials that reflect the mix of language, cultural, and demographic differences among ethnic minority people requires extensive knowledge of the intended audience. One Hispanic service provider in Los Angeles has created a Spanish-language "foto novela" (picture book) about Alzheimer's disease and dementia. The picture book format and the pitch of the text are intended for a segment of the Spanish-speaking population that is not reached by Alzheimer's Association pamphlets that have been translated into Spanish. The content of the book, a page of which is shown in figure 2-2, reflects values, customs, and experiences that are common to Mexican-Americans. According to the author, different text and illustrations would be needed for Spanish-speaking Cuban-Americans (146)

4. **Information about dementia and services for people with dementia must be available through the existing ethnic minority community infrastructure and ethnic minority agencies, where there are such agencies.**

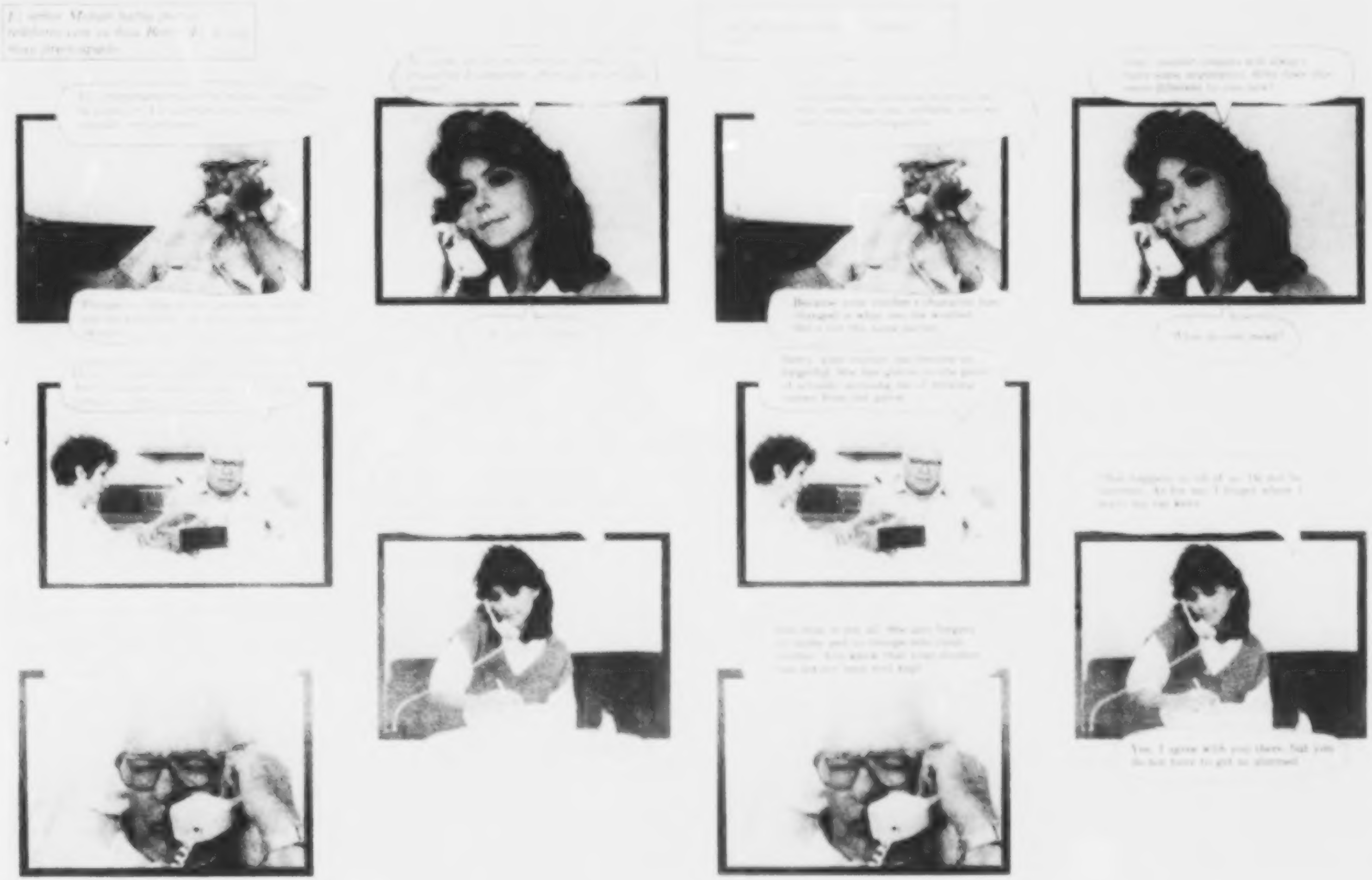
For cultural, demographic, and historical reasons, many ethnic minority people live in communities largely composed of members of the same group. In these communities, there is generally an infrastructure of individuals and associations that are recognized by the community as sources of information and assistance with a wide range of problems (380,867). Some communities also have agencies that primarily serve one ethnic group in that community. If information about dementia and about services for people with dementia is to reach patients and their caregivers in these communities, it must be available through these individuals, associations, and agencies.

It may not be obvious to outsiders which individuals and associations are recognized by an ethnic minority community as sources of information and assistance. The individuals' occupations and the associations' stated objectives may have no apparent connection with care of people with dementia. Yet information distributed through other, seemingly more appropriate channels, is less likely to reach those that need it or to be accepted by them (862).

The importance of the church as a source of support and assistance in black communities is widely recognized (642,770,782), and some commentators have suggested that churches in those communities could provide information about services or refer people with dementia and their caregivers to other sources of information (750). Service providers in Los Angeles County told OTA's contractors that pastors of some black churches are enthusiastic about learning about dementia and making information available to their members. On the other hand, some caregivers cannot leave the person with dementia alone and therefore cannot be involved in church activities (160). Other black caregivers are not connected to a church, and alternate ways of reaching these caregivers also are needed.

Although churches in black communities may play a role in providing information or referring people to sources of information about dementia and services for people with dementia, churches in some ethnic minority communities are unlikely to play such a role. A study of elderly Vietnamese immigrants in two Texas communities found, for example, that 90 percent of the respondents said their church or temple was important to them, but none said they would turn to it for help with a problem (165). They regarded the church or temple as a spiritual and cultural institution and said they would turn to public agencies for information and assistance.

Figure 2-2—Illustrations From a "Foto Novela" (Picture Book) on Alzheimer's Disease That is Targeted to Mexican Americans


Yes, I agree with you there, but you do not have to get so alarmed

SOURCE: Calmecac Educational Services, *Siempre Viva* (Los Angeles, CA: Calmecac Educational Services, 1989).

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Clearly, not all ethnic minority people live in communities largely composed of one ethnic group. Making information about dementia and about services for people with dementia available to geographically dispersed ethnic minority people undoubtedly is more difficult than making it available in self-contained minority communities. The study conducted for OTA in Los Angeles and San Diego Counties did not address this problem, and OTA has not looked into methods that have been used successfully to provide information about other health problems for geographically dispersed ethnic minority people.

PHYSICIANS' ROLE IN REFERRING PATIENTS AND CAREGIVERS TO SERVICES

As discussed in the beginning of this chapter, many families and other informal caregivers say that physicians are not knowledgeable about services for people with dementia and do not refer patients and their caregivers to services (125,257,412,497,500, 531,599,934). For example, three-quarters of the 100 family caregivers interviewed for the Connecticut Governor's Task Force on Alzheimer's Disease in 1988 said that at the time of diagnosis, the patient's physician did not refer them to any services (479).

Although other health care and social service professionals also may not be knowledgeable about services for people with dementia and may not provide appropriate referrals, the focus of caregivers' complaints has been on physicians—probably because of caregivers' expectations for physicians. A physician is usually the one who tells the caregivers the patient's diagnosis, and since physicians often refer all kinds of patients for other medical services at the time of diagnosis, caregivers may expect the physician to refer them to services. Similarly, throughout the course of a patient's illness, caregivers are likely to turn to the physician when there are changes in the patient's condition and problems they cannot handle (292). They hope and often expect that the physician will be able to provide solutions, including referrals to appropriate services. If that does not happen, the physician may get blamed. Other health care and social service professionals who might provide referrals seem to get blamed less often—probably because patients, families, and others do not have the same expectations for them.

Physicians are in a difficult position with respect to providing information and referrals for their patients with dementia. The literature identifies many other tasks for physicians who are treating people with dementia, even without considering the task of providing information and referrals. The identified tasks include making a diagnosis; treating any intercurrent illness; managing the patient's medications; offering emotional support for families and other informal caregivers; and providing education and counseling for caregivers about the patient's diagnosis and prognosis and caregiving techniques to reduce patients' behavioral problems and maintain patient functioning (74,154,292,300, 368,679,915). As discussed earlier in this chapter, helping caregivers of people with dementia identify their service needs and select a service provider is often time-consuming. In addition, in many communities, there is no source of accurate, comprehensive information about what services are available, and the service environment is so complex that it is difficult and time-consuming for anyone to keep current on available services. Given existing constraints on physicians' time, it may be unrealistic to expect physicians to provide information about services and referrals to services for their patients with dementia.

On the other hand, many caregivers expect physicians to provide information and referrals. Moreover, given the general feeling of respect for physicians, caregivers are probably more likely to use services if they have been referred to the services by a physician than by someone else. As discussed in chapter 3, some caregivers of people with dementia feel guilty about using services and believe that they should provide all the patient's care themselves. This feeling is compounded for some caregivers by doubts about whether the patient is really "sick" and, therefore, whether the use of services is justifiable. In the eyes of these caregivers, a physician's referral may give legitimacy to their use of services (290,931).

Discussions about physicians' role in providing referrals for dementia patients and their caregivers generally do not distinguish between a physician furnishing information about community services and referrals to specific providers and a physician referring patients and their caregivers to another source of information and referrals. Some commentators suggest that physicians should act as the coordinator or manager of services for people with dementia. Winograd and Jarvik say, for example:

> In addition to providing medical care and psychologic support, the physician can play a pivotal role in developing comprehensive plans for demented patients with the aid of other health professionals (e.g., discharge planners and visiting nurses). Social workers can assist with referral to the appropriate resources . . . (915).

This statement implies that the discharge planner, visiting nurse, and social worker should be the sources of information about specific service providers.

Many commentators recommend a multidisciplinary team approach to care of people with dementia (56,257,292,679,915). In that approach, a physician may discuss potentially beneficial services with caregivers and recommend their use, but the task of identifying service providers usually is performed by a social worker, nurse, or another team member. Most physicians do not practice as part of a multidisciplinary team, however. If their patients and the patients' caregivers are to receive information about services and referrals to service providers, the physician must either furnish them or refer the caregivers to another source of information and referrals.

Some and perhaps many physicians may prefer not to be the primary source of information and referrals for their patients with dementia. A study of physicians' roles in treating people with dementia asked 57 physicians to rate the relative difficulty of various tasks involved in caring for these patients (257). The study's findings show that the physicians considered helping patients and their families obtain health care and social services and advising them about nursing home placement among the most difficult and time-consuming tasks in treating these patients. The 47 family caregivers interviewed as part of the study said that physicians were least helpful in these areas. The researchers concluded from the physicians' spontaneous comments during the interviews that some of the physicians made a distinction between coordinating medical services and social services and did not regard referrals for social services as their responsibility.

It is often said that physicians know less about and refer patients less frequently to social services than to medical services (125,133,257,927). It is also said that some physicians are not knowledgeable about home care services and sometimes recommend nursing home placement when the patient could be cared for at home with available services (500,934). The same observations have been made with respect to physicians' knowledge of and referrals to services for elderly people in general, and the findings of some studies support these observations (661,927).

Some AAAs have attempted to increase physicians' awareness of services and encourage physicians to refer elderly people and people with dementia to an AAA for information and assistance with arranging services (934,944). Sometimes these efforts are initially successful. Referrals by physicians to the AAA increase for a time but then drop off. It is not clear why this occurs. Some physicians may not be convinced of the value of certain services for their patients, or their referrals to the AAA may not work in some way that leads them to stop referring.

The distinction between service consciousness and service knowledge that was made earlier in this chapter with respect to caregivers' knowledge about services may be helpful in thinking about physicians' knowledge about services and their role in providing information and referrals for people with dementia. If physicians have service consciousness (i.e., they are aware of the types of services that may be useful for people with dementia) but lack service knowledge (i.e., they do not know what specific agencies or individuals provide the services in the community), they still can talk with caregivers about potentially beneficial services and encourage the caregivers to use appropriate services. Then they will have to refer the patients and caregivers to someone who is knowledgeable about the details of service availability in the community. If, on the other hand, physicians lack service consciousness (i.e., they are not aware of the types of services that may be useful for people with dementia), they will not be able to refer or advise caregivers appropriately. They may recommend too often the services they know about and fail to recommend others that may be more appropriate for the patient's and family's needs. Anecdotal evidence suggests that some physicians lack service knowledge; others lack both service consciousness and service knowledge; and still others are well-informed about services that may be useful for people with dementia and about the availability of those services in the community.

Physicians play a pivotal role in linking people with dementia to services, and ways must be found to ensure their effectiveness in that role. It may be unrealistic to expect physicians to stay up-to-date on available services and funding for services in other than very small communities, and it probably would be undesirable from a societal perspective for physicians to spend their time in that way. A more appropriate objective may be for physicians to be aware of the kinds of services that may be beneficial for people with dementia, to discuss services in a general way with patients and their caregivers, and then to refer the patients and caregivers to another individual or agency that can provide information about specific service providers and funding for services. Obviously, for this approach to work, a source of accurate information about services and service providers must exist in the community.

CONCLUSION

In many communities, accurate information about services for people with dementia and about funding for such services is not available. Other problems usually receive more attention from policymakers and dementia advocates, but when dementia caregivers are asked, they stress the difficulties they face in trying to obtain information about services and funding. In the view of many caregivers and service providers interviewed for this OTA assessment, caregivers' lack of knowledge about services is the primary barrier to service use.

Knowledge about services has two components, referred to here as service consciousness and service knowledge. The study conducted for OTA in Cuyahoga County, Ohio, found that a significant proportion of caregivers of people with dementia, 12 to 92 percent depending on the service in question, lacked service consciousness—i.e., they had never heard of the service. Again depending on the service, 35 to 96 percent of caregivers lacked service knowledge—

Photo credit: Alzheimer's Association and Rush-Presbyterian/St. Luke's Medical Center

Physicians play a pivotal role in linking people with dementia to services.
Ways must be found to ensure their effectiveness in that role.

i.e., having been told what the service is, they could not identify a specific provider in the community (186).

A caregiver's need for service knowledge probably is greatest at the time(s) when he or she is selecting a specific provider. A caregiver's need for service consciousness, however, is longer lasting and more general. An awareness of different types of services can help a caregiver think realistically about a demented person's care, consider various alternatives, and plan for the future—all of which may increase the caregiver's sense of being in control of the caregiving situation.

Lack of service consciousness is probably addressed most effectively through public education programs. Lack of service knowledge is addressed most effectively through information and referral programs. Neither approach is sufficient by itself because people who lack service consciousness are unlikely to call an information and referral source. Conversely, the kind of information that can be provided through public education programs often is not detailed enough to allow people to locate the services they need or to determine whether they are eligible for various funding programs.

To link people with dementia to appropriate services, an information and referral program must have an up-to-date resource list that includes all agencies and individuals in the community that provide the kinds of services that may be needed for people with dementia. Whether the information and referral program is dementia-specific or not, it must be dementia-capable. The program's staff must be knowledgeable about dementia, the care needs of people with dementia, and the common problems families and others face in taking care of a person with dementia. The program must be able to provide accurate information about eligibility and coverage for services through Medicare, Medicaid, and other funding sources. If the program is not dementia-specific, it must have mechanisms for identifying people with dementia so that it can provide appropriate information and referrals. Lastly, it must be responsive to the special information and referral needs of ethnic minority people with dementia.

Even if accurate information about services and funding for services were available, however, it would not mean that there would be enough services or funding. Insufficient availability of services and funding for services is a major public policy concern that cannot be remedied by an accurate resource list or by the best public education and information and referral programs. On the other hand, without an accurate resource list, no one can know with certainty what is and is not available, except in small communities with very few service providers.

In public policy discussions, a single-minded focus on the problem of insufficient availability of services and funding for services for people with dementia precludes awareness of other problems that restrict access to the services and sources of funding that are available. Obviously, one of these problems is the lack of accurate information about services and funding for services. Underlying that problem is the incredible complexity of services and funding at the community level. An accurate resource list and public education and information and referral programs can help caregivers and others locate services and sources of funding but cannot change the inherent complexity of the service environment. If the complexity of the service environment were reduced, obtaining accurate information about services and funding would certainly be less difficult.

Chapter 3

The Need for Outreach and Case Management

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Chapter 3

The Need for Outreach and Case Management

INTRODUCTION

People with dementia and their caregivers cannot be linked to services or sources of funding for services that do not exist, and as noted throughout this report, existing services and funding for services for people with dementia are inadequate (9,831).[1] Even when services and funding are available, however, some patients and caregivers do not use them. As discussed in chapter 2, one important reason why they do not use services is that they do not know about the services. To increase people's knowledge about services and sources of funding for services, an effective linking system must include public education and information and referral (see ch. 2).

The analysis in this chapter indicates that some people with dementia and some caregivers need assistance that goes beyond public education and information and referral if they are to be linked to appropriate services. The types of individuals who are likely to need such additional assistance include:

- individuals with dementia who live alone and have no family member or other informal (unpaid) caregiver to help them;
- individuals with dementia who have an involved family member or other informal caregiver who is aware of services but reluctant to use them even though the services are needed; and
- individuals with dementia who have an involved family member or other informal caregiver who is aware of services but unable to arrange them.

From the analysis in this chapter, OTA concludes that in order to serve these types of individuals effectively, a linking system must include outreach and case management in addition to public education and information and referral. *Outreach* in this context is defined by OTA as any active method of identifying individuals who need services but are unlikely to respond to a public education program or to contact an information and referral source on their own. *Case management* in this context is defined as a process that includes the five core functions shown in table 3-1.

The first section of this chapter presents the available data on the use of services by people with dementia and their caregivers. The data show that many of these individuals do not use services. Some of them do not use services because the services do not exist or are too costly or because they are not aware of the services. Data from several studies indicate, however, that some people with dementia and their caregivers do not use services even when the services are available and affordable and they know about the services. As discussed in the second section of the chapter, some people with dementia and some caregivers have characteristics, feelings, and perceptions that make them either unable to arrange services themselves or reluctant to ask for or accept services. To a great extent, these patient and caregiver characteristics, feelings, and perceptions explain why outreach and case management are essential components of an effective linking system.

Many of the same characteristics, feelings, and perceptions that interfere with the use of services by some people with dementia and by some caregivers also complicate the case management process with these individuals, making it difficult for a case manager to assess their needs and plan, arrange, and monitor services for them. The third section of the chapter discusses what is special about case management for people with dementia and draws implications for the skills and training needs of case managers who work with people with dementia and their caregivers.

Many questions about the case management component of a linking system for people with dementia remain to be answered, including whether, in general, families should be regarded by a linking system as "co-case managers" or "co-clients;" whether counseling should be part of the case management component of a linking system; and how many people with dementia and their caregivers need or should receive case management. These and other unresolved questions pertaining to case management for people with dementia are discussed at the end of this chapter. The answers to these questions have implications for the design and operation of the case management component of a

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[1] See table 1-2 in ch. 1 for a list of the services that may be needed for people with dementia.

Table 3-1—The Five Core Functions of Case Management

1. Assessing a client's needs
2. Developing a plan of care
3. Arranging and coordinating services
4. Monitoring and evaluating the services that are delivered
5. Reassessing the client's situation as the need arises

SOURCE: Office of Technology Assessment, 1990.

linking system and for the skills and training needs of case managers employed by the system.

This chapter relies heavily on the findings of two OTA contract reports. One OTA contract report describes a respite care demonstration project for families of people with dementia conducted by Duke University and identifies factors that interfered with the timely use of respite services by some families (291). The second OTA contract report describes an exploratory study conducted for OTA in 1988 that examined: 1) what case managers in five Pennsylvania area agencies on aging (AAAs) perceived to be the unique aspects and difficulties of working with people with dementia and their families; and 2) how family caregivers perceived the process by which the AAA case managers arranged services for them (934). The Duke respite care demonstration project and the study conducted for OTA in Pennsylvania are described later in this chapter as their findings are presented.[2]

THE LIMITED USE OF SERVICES

Available data from 11 small-scale studies described below indicate that although the majority of people with dementia use physicians' services, only a minority of them use in-home and other community services. Several large-scale national studies, such as the 1982 and 1984 National Long-Term Care Surveys, also include information about subjects' use of services, but it is difficult to determine with any certainty which subjects in the surveys have dementia (468). Thus, it is not possible to develop valid figures on service use by people with dementia from those studies. For that reason, OTA's conclusions about service use are based on the 11 small-scale studies that focus exclusively on service use by people with dementia.

The source of the study sample, the severity of the subjects' dementia, and the time period and specific services covered by the 11 studies vary; hence, their findings are not directly comparable. Moreover, the use of some services—mental health services, legal services, benefits counseling, and certain other services needed by some people with dementia—was not considered in any of these studies. Nevertheless, the findings suggest that many noninstitutionalized people with dementia do not use any paid in-home or community services other than physicians' services.

1. A 1985 survey of 597 caregivers of noninstitutionalized individuals with dementia in 16 States found that only one-fourth of the caregivers had ever used any paid in-home or community services (117).

2. A 1987 survey of 100 caregivers of noninstitutionalized individuals with dementia in Connecticut found that 14 percent of these individuals were receiving services from community agencies, an additional 12 percent were receiving services from "privately hired help," and 3 percent were receiving services from both sources. The results of a companion survey of 531 Connecticut health care and social service agencies suggest that only 13 percent of all noninstitutionalized individuals with moderate or severe dementia in the State were receiving any services from such agencies in 1987 (479).

3. A 1983 study of 501 family caregivers of individuals with dementia in North Carolina found that 43 percent of the caregivers had used a paid helper (usually a maid or sitter) to care for the patient (242,243,291). Fewer than one-fifth of the caregivers had used any other in-home or community services for the individual with dementia: of these, 19 percent had used in-home nursing services, 12 percent had used adult day care, and 13 percent had used homemaker or chore services. Followup interviews with the same caregivers a year later found that only one-fourth of the caregivers had used any paid services other than physicians' visits for the person with dementia in the intervening year. The average duration of the demented individuals' illness in this study was 5 years (range: 6 months to 30 years), and most services were used in the final year before the patient died or was placed in a nursing home.

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[2] The two contract reports are available from the National Technical Information Service in Springfield, VA (see app. A.)

4. A study of 101 people with dementia seen at an outpatient dementia clinic in Minnesota between 1982 and 1984 found that 48 of them had *severe* dementia at the time of their initial clinic visit; by the time of the last followup (2 to 4 years after their initial visit), 31 percent of these 48 patients had died; 40 percent had been put in a nursing home; and 29 percent were still living at home (411). Of those who were still at home, 79 percent, or 23 percent of the original sample, were using either adult day care or in-home nursing services. The same study found that 53 of the 101 people seen at the outpatient dementia clinic between 1982 and 1984 had *mild* dementia at the time of their initial visit; by the time of their last followup (2 to 4 years after their initial visit), about half of these 53 patients had died (9 percent) or been put in a nursing home (41 percent), and half were still living at home. Of those still at home, 32 percent, or 13 percent of the original sample, were using either adult day care or in-home nursing services.

5. A 1986 survey conducted for OTA of 569 family caregivers of people with dementia found that 11 percent of the caregivers were using paid companion or home health aide services at the time of the survey, and 21 percent had used them in the past but were not using them at the time of the survey (926). Eight percent of the caregivers were using visiting nurse services at the time of the survey, and 17 percent had used them in the past. Four percent were using adult day care services, and 6 percent had used them in the past. Three percent were using respite care services, and 5 percent had used them in the past.

6. A study of 117 individuals with dementia who were assessed from March to July 1987 by the Alzheimer's Project of Kennebec Valley, Maine, found that 11 percent of these individuals were using respite/adult day care, 11 percent were using homemaker services; 4 percent were using "hired help"; 4 percent were using a personal care attendant; and 3 percent were using a nurse assistant (223).

7. An analysis of data on 453 individuals with dementia seen at California's six Alzheimer's Disease Diagnostic and Treatment Centers in 1987 found that two-thirds of these patients had used physicians' services in the previous 6 months (227). Only 10 percent or fewer of the patients had used home health aide, homemaker/chore, or adult day services in that period.

8. A study of 213 family caregivers of individuals with dementia in Michigan found that while 63 percent of the patients had used physicians' services in the previous 3 months, fewer than one-third had used home health aide services (30 percent), visiting nurse services (18 percent), adult day services (14 percent), housekeeping services (8 percent), or respite care services (7 percent) (774). Moreover, many of the caregivers who had used a service had used it very few times. The researchers compared service use by people with dementia from this study and service use by people with stroke and other diagnoses (e.g., cardiovascular and renal diseases) from other studies and found that although the people with stroke and other diagnoses were only slightly more impaired than the people with dementia in terms of activities of daily living (ADLs) and instrumental activities of daily living (IADLs), the people with stroke and other diagnoses used in-home and community services two to three times more frequently (255).

9. A 1983-84 study that compared the amount of care received by 20 elderly people who had moderate to severe dementia and 20 elderly people who had moderate to severe physical impairments found that, on average, the people with dementia received less than half the amount of paid services received by the people with physical impairments (7.5 hours per week v. 16 hours per week of paid services, respectively) (71).

10. In a 3-year respite care demonstration project conducted by Duke University in North Carolina, families of people with dementia were offered two types of respite care: in-home respite or overnight care of the patient in a nursing home (291). Although the respite care was provided regardless of a family's ability to pay, only a small percentage of the families eligible for the respite services used them. Furthermore, many of the families in this study waited until just prior to the patient's death or placement in a nursing home to use respite services: about half of the people with dementia who received respite services died or were placed in a nursing home within 8 months of first receiving the services, and half of those individuals died or were placed

in a nursing home within 30 days of first receiving the services.[3]

11. In a 1-year respite care demonstration project conducted by the Philadelphia Geriatric Center, over 300 families of people with dementia were offered three types of respite care: 1) in-home respite care, 2) adult day care, and 3) overnight nursing home care. About half of these families used the respite services offered—35 percent used in-home respite care, 2 percent used adult day care, 7 percent used overnight nursing home care, and 8 percent used more than one type of respite care. Most of the families who used respite services used very few hours: during the year, only about one-third of the families who used in-home respite care used more than 100 hours of this type of care; families who used adult day care used an average of only 10 days of such care, and families who used overnight nursing home care used an average of only 11 nights of such care (88,448).

As noted earlier, these 11 studies are not directly comparable because of differences in the time period and services covered, the source of the study sample, and the severity of the subjects' dementia. Nevertheless, the following general conclusions can be drawn from the studies' findings:

- only about one-fourth to one-half of all noninstitutionalized people with dementia use any paid in-home or community services other than physicians' services;
- among those noninstitutionalized people with dementia who do use services, many use very few services or use them infrequently;
- many noninstitutionalized people with dementia who do use services use them very late in the course of their disease; and
- on average, noninstitutionalized people with dementia use fewer paid services than noninstitutionalized people with physical impairments.

The percentage of people with dementia who use nursing homes in the course of their dementing illness is not known. The 1986 survey of 569 family caregivers conducted for OTA (study #5 above) found that half of the individuals with dementia being cared for had been in a nursing home at some time in the course of their illness, including 36 percent who were in a nursing home at the time of the survey and 15 percent who had been in a nursing home previously but were not at the time of the survey (926). The five other studies cited above that included nursing home residents found that as few as 3 percent to as many as 33 percent of the individuals in their samples were in nursing homes (223,227, 242,479,774).[4] The wide range in these figures reflects differences in the source of the sample and the time frame of the studies and differences in Medicaid regulations, bed supply, and other factors that affect the number of people with dementia in nursing homes in different States.

The 1985 National Nursing Home Survey found that 620,000 nursing home residents—47 percent of all elderly nursing home residents—had senile dementia or chronic organic brain syndrome (846). That survey also found that 830,000 nursing home residents—63 percent of all elderly nursing home residents—were so disoriented or memory-impaired that their performance of the activities of daily living, mobility, and other tasks was impaired nearly every day. Using these figures from the National Nursing Home Survey and OTA's estimates of the prevalence of dementia nationwide,[5] one could estimate that from 9 to 33 percent of Americans with dementia are in nursing homes at any one time. The wide range in that estimate reflects uncertainty about the percentage of nursing home residents with dementia (e.g., 47 to 63 percent) and uncertainty about the prevalence of dementia.

PERSONAL FACTORS THAT MAY INTERFERE WITH INDIVIDUALS' ABILITY OR WILLINGNESS TO USE SERVICES

There are many reasons why some people with dementia and some caregivers do not use services. As discussed in chapter 2, researchers performing a study for OTA in Cuyahoga County, Ohio, asked 26 caregivers of people with dementia to give their opinions about why people do not use services (186).[6] The reasons most frequently identified by these caregivers were people's lack of knowledge about services and people's inability to afford services. In addition, many of the caregivers said that certain characteristics, feelings, and perceptions are barriers to service use for people in general and were reasons they did not use services themselves. The reasons these caregivers identified are listed in table 3-2.

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[3] See box 3-A for further discussion of the Duke University Respite Care Demonstration Project.

[4] The specific estimates by study were 3 percent (223,227,774); 28 percent (242); and 33 percent (479).

[5] In 1987, OTA estimated that 1.5 million Americans had severe dementia, and 1 to 5 million had mild or moderate dementia (831).

[6] For more information on the study conducted for OTA in Cuyahoga County, OH, see app. A.

Researchers in the study conducted for OTA in Cuyahoga County, Ohio, also asked 24 representatives of community agencies that provide services for people with dementia to identify barriers that kept people with dementia and their caregivers from using services (186). As noted in chapter 2, all 24 agency representatives said that their clients' lack of knowledge about available services was often or occasionally a barrier to the use of services, and most (87 percent) of them said that their clients' lack of financial resources to pay for services was often or occasionally a barrier. In addition, many of the agency representatives said that the following personal characteristics, feelings, and perceptions were often or occasionally barriers to service use:

- clients' desire to remain independent of the formal care system (identified by 91 percent of the agency representatives);
- clients' lack of recognition that they need formal services (identified by 96 percent of the agency representatives);
- clients' inability to arrange services once they know the services are available (identified by 88 percent of the agency representatives);
- clients' feeling that the recommended service was not needed (identified by 84 percent of the agency representatives);
- clients' feeling uncomfortable about using recommended services (identified by 76 percent of the agency representatives);
- clients' unwillingness to pay for services even though they are judged to have adequate financial resources (identified by 58 percent of the agency representatives); and
- clients' feeling that others will disapprove of their use of services (identified by 41 percent of the agency representatives) (186).

In the analysis that follows, OTA identifies the personal factors—i.e., characteristics, feelings, and perceptions—that may interfere with the ability or willingness of some individuals with dementia or their caregivers to use available services. A later section of the chapter discusses the implications of these patient and caregiver characteristics, feelings, and perceptions for an effective linking system.

Personal Factors Related to Individuals With Dementia

Most studies and commentaries about people's characteristics, feelings, and perceptions that may limit their use of services pertain to family caregivers. Relatively little has been written about characteristics, feelings, and perceptions of individuals with dementia that may limit their use of services. At least 20 percent of people with dementia live alone, however, and up to half of these individuals have no family member or other informal caregiver to help them (see ch. 1). Such

Table 3-2—Caregivers' Opinions About People's Characteristics, Feelings, and Perceptions That Are Barriers to the Use of Services, Cuyahoga County, Ohio, 1988 (N = 26)

	How often is it true for people in general?	Is there a reason you did not use the services?
Possible barriers to the use of services	Usually (in percent)	Yes (in percent)
People know what services are available but don't know how to make arrangements to use them	42	50
People don't think they need the services recommended to them	38	50
People don't use the services because they do not want to lose their independence	38	19
People don't recognize the fact that they need services	33	42
Using services makes people feel uncomfortable	27	31
People are afraid others will not approve if they use services	19	19
People have money but are not willing to pay for services	12	8

SOURCE: S. Eckert and K. Smyth, "Methods of Locating and Arranging Health and Long-Term Care Services for Persons With Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, 1988.

individuals make decisions about services for themselves—either explicitly or implicitly—unless a case manager, service provider, or other health care or social service professional makes the decisions for them,

OTA's analysis of characteristics, feelings, and perceptions of individuals with dementia that may interfere with their ability or willingness to use available services is based primarily on two sources:

- case managers' responses to an exploratory study conducted for OTA in five Pennsylvania AAAs (934); and
- OTA's informal discussions with case managers, health care and social service professionals, and others, including members of the advisory panel for this study.

All of the case managers and other professionals just mentioned emphasized that many of their clients with dementia live alone and have no one to help them with decisions about services. They noted that clients who live alone with no one to help them are generally more isolated and more resistant to using services than people with dementia who have an informal caregiver to assist them.

Individuals with dementia vary greatly with respect to their cognitive and self-care abilities, emotional and behavioral characteristics, and other characteristics (e.g., age, ethnicity, socioeconomic status, and coexisting physical conditions) that are largely unrelated to their dementia. As an individual's dementing illness progresses, some of these characteristics change in ways that affect the individual's attitudes about services. It is important to point out, therefore, that although some people with dementia have the characteristics, feelings, and perceptions discussed below, not all people with dementia have them. Furthermore, people with dementia who have them at one time do not necessarily have them at another.

1. **Some people with dementia do not know that they need services.**

Because of lack of judgment, other cognitive deficits associated with dementia, or denial, some people with dementia are not aware of their own limitations. Consequently, they may not know they need services (487,934).

2. **People with dementia are unlikely to know about potentially helpful services.**

Because of loss of memory and diminished ability to learn new information, many people with dementia cannot remember or learn about potentially beneficial services (934). People with dementia who live alone and have no informal caregiver are both physically and emotionally isolated. Even if they are cognitively able to learn about services, such individuals may not receive the necessary information.

3. **Many people with dementia are not able to arrange services for themselves.**

Because of cognitive deficits associated with dementia, people with dementia are unlikely to be able to remember or find the names and telephone numbers of service providers. They may not understand or remember what they are told about eligibility requirements, cost, reimbursement, and other factors. They may not be able to give service providers information the providers need to initiate services. Some people with dementia cannot communicate clearly with providers. Some forget what they are trying to do before the service arrangements are complete.

4. **Some people with dementia do not want anyone to know about their cognitive and other deficits and may isolate themselves and refuse services for that reason.**

At least in the early stages of dementing diseases, some people with dementia are ashamed of their memory loss and other impairments associated with dementia and try to conceal those impairments from other people to avoid embarrassment (535). Some people try to conceal their cognitive and other impairments because they are afraid that if the impairments are recognized, other people will try to take control of their lives (456). Anecdotal evidence indicates that some people with dementia isolate themselves completely, because they are afraid that if anyone finds out how poorly they are managing, they will be placed in a nursing home.

5. **Some people with dementia are afraid of being exploited by service providers and may not use services for that reason.**

Because of their memory impairment and lack of judgment, people with dementia are easily exploited by anyone who interacts with them (40,286). Many people with dementia have been, or fear they will be, exploited by service providers, especially nonprofessional in-home workers (934). For that reason, they may be reluctant to use services.

Photo credit: Bill Adams

Some people with dementia who live alone and have no relative or friend to help them refuse services because they are afraid of being exploited by service providers or afraid that if anyone finds out how poorly they are managing, they will be placed in a nursing home.

In addition, research indicates that one-fourth to one-half of people with Alzheimer's disease are paranoid. Beliefs that other people are stealing their possessions or planning to harm them are common (295,429,525,728,787). Realistic fears about exploitation may exacerbate an individual's paranoia, thus increasing his or her reluctance to use services.

6. **Some people with dementia have realistic or unrealistic concerns about money that make them reluctant to use services.**

People with dementia who live alone and have no relative or friend to help them may have both realistic and unrealistic concerns about money that make them reluctant to use services. On average, elderly people who live alone have less income than elderly people who live with someone else (687,838). Realistically, therefore, these individuals may not be able to afford services.

Some people with dementia whose memory for events in the distant past is better than their memory for events in the present may compare current prices with prices they remember from long ago and refuse to pay even very reasonable amounts for services because they think they are being overcharged. If no one else is legally empowered to spend the individual's money (e.g., through guardianship, conservatorship, or a durable power of attorney), a person with dementia can effectively refuse services by refusing to pay for them (181).

Personal Factors Related to Informal Caregivers

Many studies and commentaries identify characteristics, feelings, and perceptions of family members and other informal caregivers that may interfere with the caregivers' ability or willingness to use available services. The analysis that follows draws on those studies and commentaries.

Not all informal caregivers of people with dementia have the characteristics, feelings, or perceptions that are discussed in this section. Nor are caregivers' feelings and perceptions necessarily consistent, clearly defined, or differentiated. Moreover, caregivers' feelings and perceptions change over time. If and when caregivers have the following characteristics, feelings, or perceptions, however, they are likely to be reluctant to use services.

1. **Some caregivers do not regard the individual with dementia as being sick or having a disease and therefore do not perceive a need for services.**

Some caregivers do not acknowledge a patient's confusion and unusual behavior (if any). Some ascribe the person's symptoms to normal aging. Others believe the symptoms are under the person's control—saying, for example, "If she paid attention, she wouldn't be so forgetful," or "He just does that to annoy me" (88). The fluctuating nature of cognitive and other deficits associated with dementing diseases and the lack of overt physical signs of many of the diseases make it easy for caregivers not to acknowledge that an individual has a dementing disease, especially in the early stages of the disease (286,643,936).

If a caregiver does not acknowledge that the person with dementia is sick or has a disease, the caregiver is unlikely to perceive a need for services. Ironically, some caregivers seem to resist using services because doing so would require them to admit to themselves that their relative has a dementing disease and may not recover (936).

2. **Some caregivers believe that the family is morally obligated to provide all needed services for a person with dementia and that it is wrong to turn to agencies or outsiders for help.**

Probably most people believe that families are to some degree morally obligated to take care of their members. Family caregivers of people with dementia frequently express this sense of obligation. Some feel that they must take care of their spouse, parent, or other relative with dementia to repay that person for taking care of them in the past. Spouse caregivers sometimes regard caregiving as a fulfillment of their marriage vows or other solemn pacts they made with their spouse. Adult children may have promised their parents to take care of them in old age (291,514,669). Whatever the source of their sense of obligation, violating it can cause intense and prolonged feelings of guilt (514,670,933). These feelings probably arise most often when family members place the patient in a nursing home, but some caregivers also feel guilty about leaving the patient at home with a home health aide or homemaker or at an adult day center (514). The fact that in caring for a person with dementia, there are few required skills that family caregivers do not have (or believe they have) makes some caregivers feel even more guilty about using services that they could—at least in theory—provide themselves.

Because of different societal expectations about the appropriate roles of men and women, women are more likely than men to feel obligated to provide all the patient's care themselves (85,669,936). Likewise, certain ethnic and social groups are more likely than others to believe that families—and sometimes specific family members—are obligated to provide all the patient's care themselves and that it is wrong to use paid services (330).

One might expect that family caregivers who have had a difficult relationship with the patient in the past or who feel angry or frustrated about aspects of the caregiving situation would feel less obligated to provide all the patient's care themselves, but research and anecdotal evidence indicate that the opposite is often true. Some of these caregivers feel guilty about their negative emotions and consequently redouble their efforts to provide all the person's care themselves (88,96,137,272,535,936).

3. **Some caregivers do not feel burdened by caregiving tasks that seem extremely burdensome to other people. Caregivers who do not feel burdened are unlikely to perceive a need for services.**

Caregiver burden has been defined and studied in terms of: 1) patient characteristics and behaviors that create demands on the caregiver; 2) the caregiver's subjective experience of those demands; and 3) the objective impact of caregiving on the physical and mental health, social participation, and financial status of the caregiver (932). Research has found a surprising lack of correlation between patient characteristics and behaviors that create demands on the caregivers and the caregiver's subjective experience of those demands (244,643,668,938). Some caregivers' subjective experience of burden is lower than might be expected given the objectively difficult caregiving situations they face (241,937). Moreover, many families have positive feelings about caregiving and pride in their ability to manage difficult caregiving situations (125,242,448,514,555,643).

To note the positive feelings of some caregivers and the lack of correlation between patient characteristics and behaviors and caregivers' subjective feelings of burden is not to suggest that caregivers of people with dementia are not burdened. In fact, research indicates that caregivers of people with dementia experience more subjective feelings of burden and more negative consequences of caregiving (e.g., increased use of alcohol and psychotropic drugs and reduced participation in social activities) than caregivers of other elderly people or other comparison groups (71,242,291,296,411,415,610,612). The intent here is simply to emphasize the diversity of caregivers' subjective experience of the demands of caregiving.

Many factors mediate between patient characteristics and behaviors that create demands on a caregiver and the caregiver's subjective experience of burden and explain some of the lack of correlation between them. These factors include the age and sex of the caregiver; the caregiver's relationship with the patient; whether the caregiver is employed; and whether the caregiver lives with the patient. Duke University's studies indicate, for example, that male (primarily spouse) caregivers of people with dementia experience less subjective burden than female caregivers (291). Although older spouse caregivers are generally more objectively burdened, younger adult child caregivers experience more subjective burden (291). Employed caregivers generally experience less subjective burden than unemployed caregivers (86,198,242), but caregivers who quit work or reduce their hours because of caregiving responsibilities experience more subjective burden than other caregivers (86).

Caregivers' appraisals of patient characteristics and behaviors affect whether they experience the characteristics and behaviors as burdensome (297, 487,533,649,938). Anecdotal evidence suggests, for example, that caregivers who view a patient's confusion and unusual behaviors as a direct consequence of a disease are generally less bothered by them than caregivers who view the same problems as in the patient's control. Caregivers' use of certain coping mechanisms, such as seeking information, problem solving and emphasizing positive feelings is associated with less subjective experience of burden (295,487,610,649,938). Lastly, the amount of social support provided by relatives, friends, and voluntary associations seems to be associated with the caregiver's subjective experience of burden (242,297,487,610,749,936,937), although some studies suggest that it is the caregivers' perception of social support, rather than the actual amount of support received, that correlates with their subjective experience of burden (291).

Three general hypotheses have been proposed about how family caregivers' subjective experience of burden changes over time (293). The "wear-and-tear hypothesis" suggests that the longer the period of caregiving, the greater the caregiver's subjective experience of burden. The "adaptation hypothesis" suggests that caregiving initially involves new demands for which the caregiver is unprepared, but that as time passes, the caregiver develops ways of meeting the demands and is less burdened. The "trait hypothesis" suggests that caregivers' experience of burden remains the same despite changes in the patient's condition and the passage of time.

Caregivers' subjective experience of burden has been shown to predict service use (291). Caregivers who do not feel burdened are unlikely to perceive a need for services even if their caregiving situations seem burdensome to others.

4. **Caregivers who have devoted themselves to the care of the patient, often for years, sometimes find it difficult to "give up" and use paid services.**

Caring for a person with dementia is an objectively difficult task that takes caregivers away from other interests, activities, and relationships. To function in this role for a prolonged period, caregivers may have to commit themselves to it single-mindedly, not allowing themselves to question what they are doing or to focus on the negative aspects of caregiving. In this state of mind, they may regard the use of services as "giving up" and resist it for that reason.

The feeling that using paid services constitutes "giving up" often occurs in the context of nursing home placement (96). One 76-year-old woman who placed her husband, who had Alzheimer's disease, in a nursing home described that feeling as "the trauma of finally having to accept the fact that you cannot care for him any longer" (670). Some family caregivers also regard the use of in-home and community-based services as "giving up," sometimes because they regard the use of these services as the first step toward nursing home placement (88,186).

5. **Some caregivers are reluctant to use services because they fear the disapproval of relatives or friends.**

Family caregivers who have come to accept the need for services still may not use services because they fear criticism from others. This often occurs when one family member, particularly the spouse or an adult child, has provided all the patient's care. Other relatives and friends who have been uninvolved may not be aware of changes in the patient's cognitive ability and behavior or of the difficulty of caring for the person. The primary caregiver may not have told them about the problem, or they may not have been willing or able to acknowledge it. In either case, they do not understand the need for services and may criticize the primary caregiver for shirking his or her obligation to the patient by using paid services. Such criticism, or even the anticipation of it, compounds the caregiver's guilt feelings and discourages him or her from using services (514,936).

6. **Some caregivers are too overwhelmed with various feelings to think clearly about how services might benefit them or the patient.**

Alzheimer's disease and other diseases that cause dementia create devastating losses for the patient and patient's family. Every account of these diseases by the spouses and adult children of patients conveys the sadness and trauma for the family of witnessing the deterioration of their relative with dementia and losing meaningful aspects of their relationship with the person. In addition, problems associated with caregiving often cause feelings of frustration and anger. Changing roles and responsibilities within a family due to the incapacity of one family member cause feelings of anxiety and resentment. Some caregivers feel ashamed of their negative emotions, guilty for not doing more for the patient, and depressed about their own lives and the caregiving situation. Some are so overwhelmed by these feelings that they cannot think clearly about how to solve their problems (39,88,129,137,201,535, 610,916,936).

Many caregivers become physically and emotionally isolated from other people because of their caregiving responsibilities. Because of that isolation, they may assume that they are the only ones who have negative feelings. Family counseling and family support groups often help caregivers understand that other caregivers have similar feelings (88,137,256,272,933,936). For some caregivers, that understanding is the first step in coming to terms with their own feelings so that they can begin to think clearly about their caregiving problems and consider possible solutions, including the use of services.

7. Some caregivers do not use services because they are unable to arrange the services.

Eighty-eight percent of the agency representatives and 73 percent of informal caregivers interviewed in Cuyahoga County, Ohio, said that people's lack of knowledge about how to arrange services is a barrier to their use of services for people with dementia. One half of the caregivers said that not knowing how to arrange services was a reason why they did not use services (186).

The complexity and fragmentation of services in many communities makes it difficult for anyone to arrange services (see ch. 2). If a person with dementia has physical or other problems in addition to dementia and so requires services from several different providers, the task of arranging and coordinating the needed services can be extremely difficult. Because of the constant demands of caring for a person with dementia, some caregivers have neither the time nor the energy to arrange services. Language and cultural differences limit some caregivers' ability to arrange services. In families in which the person with dementia was the "organizer" or "arranger" prior to his or her illness, the family member who has become the caregiver may have no experience in these roles.

Some people with dementia have a primary caregiver, who provides most of their care, and other relatives and friends who provide occasional assistance. These "secondary caregivers" sometimes help to arrange services. In 1986, 57 percent of family members who were first-time callers to a California agency that provides information about services for brain-impaired adults were not the primary caregivers (199). Likewise, a study of 25 families of persons with Alzheimer's disease who had a secondary caregiver found that the secondary caregiver sometimes helped by arranging appointments and handling legal and financial matters, in addition to providing respite for the primary caregiver (749). Anecdotal evidence suggests that because secondary caregivers often help to arrange services, people with dementia who have a secondary caregiver are more likely than other people with dementia to receive formal services (483).

8. Some caregivers do not use services because they do not believe the services will help.

Family members and other informal caregivers usually focus on the needs of the patient. Some caregivers fear, often with good reason, that the patient will be upset by any new service provider or new service setting, or that the patient will feel abandoned. Moreover, caregivers often are skeptical about service providers' capability to care for their relative with dementia and fearful that the patient may be abused or neglected. As a result, some caregivers conclude that services will not benefit the patient (88,117,291,670,936).

Caregivers who consider their own needs still may conclude that services will not help because the patient may be more agitated and difficult for them to take care of afterwards than he or she otherwise would have been. For some caregivers, services such as adult day care that require the caregiver to dress the patient and take him or her to another setting are more trouble than they are worth. Lastly, some caregivers anticipate, sometimes correctly, that they will not be able to enjoy the time away from their caregiving responsibilities because of guilt about leaving the patient with strangers and worry about the quality of care he or she is receiving. Caregivers who have a bad experience with one service or service provider for any of these reasons often are reluctant to try again (88,186,291,533,936).

9. Some caregivers do not use services because they are embarrassed about the patient's behavior.

Because of the stigma associated with mental illness in our society, families of people with dementia often are embarrassed by patient behaviors, such as hallucinations, delusions, and agitation, that suggest the patient is mentally ill. Families of people with dementia who are verbally or physically aggressive also may be embarrassed by these behaviors (72,291,533,936). Some caregivers try to conceal the behaviors from other people in order to protect themselves and the person with dementia from potential embarrassment. They may choose not to use services for this reason.

10. Some caregivers do not use services because they do not want service providers in their home.

Some caregivers are reluctant to use in-home services because of the loss of privacy and control that using such services may entail (450). One caregiver may not want a "bossy" homemaker or home health aide in his or her home. Another caregiver may not want to "share the kitchen" with an in-home service provider. Still another caregiver may be afraid that the service provider will notice that the caregiver has a substance abuse problem or some other problem that the caregiver would prefer to conceal.

11. Some caregivers feel uncomfortable about making decisions for the patient, including decisions about the use of services.

Informal caregivers may be reluctant to assume authority for decisions for the patient (39,669). One study that compared the caregiving styles of husbands and wives of people with dementia (533) found that husbands generally were more comfortable than the wives about assuming control of decisions for their cognitively impaired spouse. The wives worried about their husbands' reactions to the decisions they made and to their assumption of decisionmaking authority. Anecdotal evidence suggests that some adult children of people with dementia also are troubled by taking over decisionmaking authority for their cognitively impaired parent.

Because of one or more of the characteristics, feelings, or perceptions discussed in this section, some caregivers never use paid services for their relative with dementia. Other caregivers eventually use services, but not until long after the time when an objective observer would have said they needed help.

The results of the Duke University Respite Care Demonstration Project, mentioned earlier in this chapter and described in box 3-A, emphasize the extent of some family caregivers' reluctance to use services and the tendency of some family caregivers to put off using services for as long as they can, even when the services are available, affordable, and specifically designed to respond to the caregivers' needs and preferences (291). Some of the features of the Duke Respite Care Demonstration Project that were at least partially successful in overcoming caregivers' reluctance to use services are described in box 3-A.

The objectives of respite services are to prevent or reduce caregiver burden, to increase the effectiveness and quality of caregiving, and to prolong caregivers' ability to provide home care for their impaired relatives. These goals cannot be met if caregivers delay using services until just before the person with dementia dies or is put into a nursing home. Thus, a major conclusion of the Duke Respite Care Demonstration Project, in the opinion of its directors, was that ways must be found to encourage caregivers to use services on a timely basis (291).

One of the stated reasons why caregivers who were eligible for respite services in the Duke project did not use them or waited so long to use them was the cost of the services. Interestingly, however, their primary concern was not about current costs but about *future costs* (291). Caregivers participating in the project were charged for the respite services on the basis of self-perceived ability to pay—i.e., they were told the hourly cost for the services, asked what portion of the hourly rate they could pay, and charged that amount. Subsidies were available for up to $40 a week for 20 families per site. Overall, the caregivers paid only 20 percent of the cost of the services, and many families received totally subsidized care. Some caregivers wanted more respite services than they received but felt they could not afford the cost of services above the $40 per week cap on subsidies. These caregivers had no idea how long care would be needed for their relative with dementia, and many of the older spouse caregivers knew that they would have to spend most of their assets before Medicaid would pay for nursing home

Box 3-A—Findings From the Duke University Respite Care Demonstration Project Regarding Family Caregivers' Reluctance To Use Services

From 1985 through 1987, Duke University conducted a respite care demonstration project in four counties in North Carolina. In earlier Duke studies, family caregivers of people with dementia had said they needed respite services to provide temporary relief from the constant care and supervision of their relative with dementia. The caregivers had said they wanted in-home respite services provided by individuals who were knowledgeable about the care of people with dementia. They wanted services that would be inexpensive or subsidized and that would be available at night and on weekends, as well as on weekdays.

The Duke Respite Care Demonstration Project was designed to respond to these caregiver preferences. Respite care was provided by nursing assistants who volunteered for the project and were trained by Duke University staff to care for people with dementia. The respite services were available weekdays, nights, and weekends. To be eligible for the services, an individual with dementia had to live in one of the four counties served by the project and had to have a memory impairment severe enough so that he or she could not stay alone safely.

Over the 3-year period of the demonstration project, 100 families received respite services. Families used services for an average of 8 months and received an average of 8 hours of respite care per week. Although more than 95 percent of the families who used the services reported that they were helpful, only a small portion of the families who were potentially eligible for the services used them. Moreover, 50 percent of the individuals with dementia who received respite services through the project died or were placed in a nursing home within 8 months of entry into the project, and half of those died or were placed in a nursing home within 30 days of entry into the project. Some families used the respite services as a stopgap measure while they waited for a nursing home bed for the patient. Indeed, some families waited so long to ask for help that a hospice model of care would have been more appropriate for the patient than the companion-type respite services provided by the demonstration project.

Several features of the demonstration project were at least partially successful in addressing caregivers' concerns about the use of services. The training provided for the respite workers reassured caregivers that the respite workers could care for people with dementia effectively. The training was unique in that it was open to anyone, and prospective client families were encouraged to attend. This open training offered families a preview of the workers and their skills and created a sense of trust between the workers and the families.

The flexibility of the respite services that were offered and the workers' responsiveness to the needs of both the patients and their families also helped to overcome some caregivers' reluctance to use respite services. Respite workers performed housekeeping, meal preparation, personal care, and other functions. They also took patients and their caregivers to the doctor or beauty shop and provided companionship for the caregiver as well as the patient. Because the demonstration project considered the family unit as the client, caregivers were accepted as legitimate recipients of care.

The nurses who supervised the respite workers and functioned as case managers for the patients and families were another strength of the Duke project. During their monthly visits to monitor the respite services, the nurse supervisor/case managers provided a variety of services for the patients and caregivers, including screening caregivers for high blood pressure and other health problems, reviewing and revising the patient's plan of care, and providing individualized teaching and counseling. As caregivers developed a trusting relationship with a nurse supervisor/case manager, they became more open to referrals, and many increased their use of other community services.

The willingness of the nurse supervisor/case managers to accommodate patients' and caregivers' preferences with respect to respite workers also helped to overcome caregivers' reluctance to use services. Although all the respite workers had similar training, some patients and families had strong positive or negative responses to certain workers. Sometimes it was the worker's gender, age, beliefs, race, or appearance that prompted these strong reactions. When the nurse supervisor/case managers assigned respite workers in accordance with patients' and caregivers' preferences, the patients and caregivers were more comfortable with the services. Some caregivers fear that accepting any outside help means relinquishing family control to strangers. Having the nurse supervisor/case managers acknowledge their preferences with respect to respite workers reassured caregivers that they were still in control.

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The dependability and continuity of respite services were important to caregivers in the Duke study. Caregivers came to cherish their time off, and tardiness or absence of the worker was disappointing. For some caregivers, it was easier not to plan on time off than to plan the time and be disappointed. Continuity of respite workers was also critical to caregivers' acceptance of services. With too much turnover of assigned respite workers, some families lost adaptive energy and stopped using the services.

One important finding of the Duke demonstration project was that many caregivers of individuals with dementia can accept respite services more easily if the services are presented as being for the patient rather than the caregiver. At the beginning of the project, the respite services were promoted as providing relief for caregivers. It quickly became apparent that many caregivers were reluctant to spend money for relief for themselves when faced with the deterioration of a family member. When the initial approach was changed, and the respite services were presented in terms of their potential benefits for patients, caregivers responded more enthusiastically.

Many of the family caregivers in the Duke project considered the use of services more acceptable if the services were connected to the health care system rather than to the social service system. Social services seemed to have a "charity stigma" that was troublesome to some caregivers. Moreover, some caregivers who believed that their relative was "sick" seemed to prefer that recommendations about services be made by a physician rather than a social worker.

In 1988, Duke University began another 3-year demonstration project to test an intervention intended to facilitate the timely use of all kinds of services for people with dementia. This new project is based in a health care setting (an outpatient memory disorders clinic) because of the previous project's findings that caregivers prefer health-related services. Clinic physicians refer caregivers to social workers who are knowledgeable about services for people with dementia. The social workers then develop an individualized service plan with the caregiver and facilitate and monitor the plan over an 18-month period.

SOURCE: L.P. Gwyther, "Barriers to the Appropriate Use of Community-Based Services by Families of Persons With Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, June 1988.

care. Given these concerns about future costs, many of the caregivers felt they could not afford even $10 a week for respite services.

Implications for an Effective System To Link People With Dementia to Services

The characteristics, feelings, and perceptions discussed in the preceding sections stop some people with dementia and some caregivers from using services. Some of these individuals probably do not need the services, but others do. For example, some caregivers who say that they do not need services or that they do not need services "yet" actually do need services for their own well-being and for the well-being and safety of the patient (88,514). It is unclear whether or to what extent caregivers should be encouraged to use services the caregivers say they do not want or need. On the one hand, encouraging people who say they do not want services to use them seems absurd when there are not enough services to meet the needs of people who are asking for them. On the other hand, some commentators have noted that it is often the most isolated and objectively burdened caregivers who say they do not want or need services (88,291,418,688). Likewise, some people with dementia who refuse services, or are unaware that they need services, or are unable to arrange services are very confused, afraid, and perhaps in physical danger because of their dementia.

Everyone has a different opinion about who needs services, but there is little question that some people with dementia and some caregivers who do not use services for any of the reasons discussed in the preceding sections do in fact need services. Improved public education and information and referral programs might make it possible for some of these individuals to contact service providers on their own, but some patients and families still would not be willing or able to do so. For this reason, OTA concludes that in addition to public education and information and referral, outreach and case management are essential components of an effective system to link people with dementia and their caregivers to services.

The Need for Outreach

Outreach is defined in this OTA report as any active, individualized method of identifying people who need services but are unlikely to respond to public education programs or to contact an informa-

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tion and referral source on their own.[7] Outreach may be needed for people with dementia who live alone and have no relative or friend to help them; these individuals are particularly unlikely to request services on their own. Outreach also may be needed for overburdened caregivers who are not connected to a community agency or individual health care or social service provider. It is not clear how many patients or caregivers are included in these categories. It is clear, however, that the best possible public education and information and referral programs would not be effective in linking many of these individuals to services.

Outreach to identify people with dementia who are in need of services can take any of several forms. One way to conduct outreach is to screen individuals at places like senior centers and senior nutrition sites. Another way is to have health care and social service professionals and other service providers who interact with elderly people and their families identify people with dementia who may need services.

Although the two methods of outreach just mentioned would reach some people with dementia and their caregivers, neither approach would reach isolated patients and caregivers who do not go to senior centers or senior nutrition sites and who do not interact with health care and social service professionals or other service providers. A third method of outreach is to send paid or volunteer workers out specifically to look for potential clients (97). Although this method has been successful in reaching people with various kinds of service needs who would not have been reached otherwise, the method requires a major commitment of resources by the sponsoring agency and is therefore difficult to sustain for long periods of time.

An outreach method that can be sustained over time and is likely to reach isolated people with dementia and isolated caregivers is a "gatekeeper program" that makes use of the observations of individuals such as mail carriers and utility meter readers who come into contact with many individuals in the course of their regular daily activities. The gatekeeper programs that have been implemented in Spokane, Washington, several rural counties in Iowa, and in other jurisdictions offer models for outreach that closely match the needs of isolated people with dementia and their caregivers (97, 148,456,688)[8]. The Spokane program recruits mail carriers, utility meter readers, and other individuals who interact with many people in the course of their regular activities and trains them to identify isolated elderly people who may need assistance and to notify a central agency. In addition to mail carriers and utility meter readers, gatekeepers may include apartment managers, police, pharmacists, grocers, delivery persons, and others. To become gatekeepers, these individuals do not have to become case workers or counselors; they do have to be trained to notice signs that an elderly person is confused, ill, or otherwise at risk. When a gatekeeper identifies an individual who seems to be at risk, the gatekeeper phones a central agency. The central agency takes responsibility for contacting the person and assessing his or her need for assistance.

The Need for Case Management

The term case management is used in a wide range of contexts, and its precise meaning is often unclear. Many commentators agree, however, that case management includes the five functions shown in table 3-1—namely, assessing a client's needs, developing a plan of care, arranging and coordinating services, monitoring and evaluating the services delivered, and reassessing the client's situation as the need arises (22,43,59,110,271,382,572,574,581, 657,757,769,891,902). As defined by OTA in this report, case management is a process that includes these five functions.

Individuals with dementia who are likely to need case management include those who live alone and have no relative or friend to help them and those whose relatives live too far away to monitor their care or reevaluate their needs on a regular basis. Case management is also likely to be needed by some individuals with dementia who have an informal caregiver, including those whose caregivers are unable to define their service needs, reluctant to use needed services, or unable to arrange services for any reason. Because of the complexity and fragmentation of services in many communities, individuals with dementia who need several different services are likely to need case management to arrange and coordinate the services of multiple providers. It is not clear how many people with dementia or how many caregivers are included in these categories.

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[7] Some agencies and commentators use the term outreach in a sense that is different from the sense in which it is used by OTA in this report. They use it to refer to programs or services that an agency provides outside the agency. Some of these programs and services—e.g., lectures given by agency staff members to senior citizens, caregiver support, and other community groups—are effective in reaching some people with dementia and their caregivers but are unlikely to reach isolated, confused patients or isolated caregivers. In the context of OTA's model in this report, such programs and services are considered public education.

[8] The gatekeeper program in Spokane, WA, is described further in box 8-C in ch. 8.

Despite the general agreement about the five case management functions listed earlier, there are many unresolved definitional and practice issues with respect to case management. First, some commentators include other functions—e.g., case finding, screening, patient and family education, and counseling—in their definitions of case management.[9] Second, the implementation of each of the case management functions varies, depending on factors such as the goals and training of the case manager, the number of clients the case manager has, the type of the agency for which the case manager works (if any) and the other functions of that agency, and the extent to which the agency or independent case manager provides services in addition to providing case management. The same factors also influence the relative importance case managers place on different functions. Depending on these factors, for example, one case manager may focus primarily on arranging and coordinating services, spending most of her or his time making arrangements for specific services and less time on assessing the client's needs and developing a plan of care. Another case manager may focus more on the assessment and care planning functions, spending most of her or his time talking with patients or caregivers about the problems they are facing and what services, if any, would be helpful.

A third unresolved issue is the relationship between case management as an administrative process and case management as a clinical process. In agencies that allocate services and funding for services, case managers are frequently responsible for "administrative" tasks such as determining people's eligibility for services, authorizing services and funding for services, and monitoring the provision of services. When case managers are responsible for these administrative tasks, the five case management functions shown in table 3-1 are modified to include the tasks. Thus, for example, the function of assessing a client's needs is modified to include administrative procedures for determining a client's eligibility for services. The functions of developing a plan of care and of arranging and coordinating services are modified to include administrative procedures for selecting service providers and authorizing benefits. The functions of monitoring the services delivered and of reevaluating the client's needs are modified to include procedures to recertify the client's eligibility for services and to account for the services and funds that are used.

Photo credit: Bill Adams

A method of outreach that closely matches the needs of isolated people with dementia is a "gatekeeper" program that relies on mail carriers and others who have daily interactions with many people to identify elderly people in need of assistance.

In some agencies that allocate services and funding for services, case management seems to be primarily a series of administrative tasks intended to allocate benefits in accordance with agency or program regulations. In other agencies, case management seems to be primarily a "clinical" process in which the case manager functions more as a professional helper, counselor, and client advocate than as an administrator of benefits. If it were possible to make a clear distinction between case management as an administrative process and case management as a clinical process and call one case management and the other something else, it would be easier for everyone to understand and communicate clearly about case management. In reality, however, that distinction does not hold up. Many case managers who administer benefits for their agencies perceive themselves as professional helpers, counselors, and advocates and perform the five core functions in much the same way as case managers who do not administer benefits.

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[9] In the context of the model for a linking system described in this report, OTA considers those activities that are usually involved in case finding and screening to be part of the public education, information and referral, and outreach components of the system and the assessment function of the case management component of the system. Patient and family education are considered services that may be needed for people with dementia (see table 1-2 in ch.1). The question of whether counseling should be part of the case management component of a linking system is discussed later in this chapter.

In a study by the University of Washington, 127 case managers in agencies that allocate services and funding for services in Oregon and Washington State were asked to rate the importance of 11 possible goals of case management (47). All these case managers' jobs involved administrative tasks related to allocating services and funding for services, but the goals they identified as most important had to do with helping and advocacy. Table 3-3 lists the goals of case management in order of their average ranking by case managers in Oregon and Washington. In the view of these case managers, at least, the administrative and clinical aspects of case management are intertwined.

In addition to these definitional and practice issues with respect to case management, there are many other unanswered questions about case management in a system to link people with dementia to services. These questions are discussed in a later section of this chapter.

WHAT IS SPECIAL ABOUT CASE MANAGEMENT FOR PEOPLE WITH DEMENTIA?

Except for anecdotes and case histories, very little has been written specifically about case management for people with dementia. OTA is not aware of studies specifically designed to compare case management for people with dementia and case management for nondemented people. Many research and demonstration projects that involve case management have included subjects with dementia, but with a few exceptions, the findings of those research and demonstration projects have not been analyzed for demented v. nondemented subjects.

Table 3-3—Ranking of Certain Goals of Case Management by Case Managers in Oregon and Washington State

Rank	Goals
1	To assure that services given are appropriate for the needs of a particular client.
2	To facilitate the development of a broader array of noninstitutional services.
3	To follow clients to guarantee the continued appropriateness of services.
4	To improve client access to the continuum of long-term care services.
5	To target individuals most at risk of nursing home placement in order to prevent inappropriate institutionalization.
6	To support the client's caregivers.
7	To serve as bridges between institutional and community-based care systems.
8	To promote quality and efficiency in the delivery of long-term care services.
9	To enhance the coordination of long-term care service delivery.
10	To prevent inappropriate use of hospital inpatient services.
11	To contain costs by controlling client access to services, especially high cost services.

SOURCE: C.D. Austin, E.F. Borgatta, E.A. Roberts, et al., *Improving Access for Elders: The Role of Case Management: Final Report* (Seattle, WA: University of Washington, January 1987).

Some aspects of case management are undoubtedly similar for demented and nondemented people, but it is easy to imagine ways in which the characteristics and care needs of people with dementia might change the case management process, make it more difficult, and/or limit its effectiveness. The process of assessing an individual's needs may be more difficult in the case of individuals with dementia, e.g., because such individuals often are not a good source of information. The process of planning care may be more complicated for individuals with dementia because of the fact that some demented individuals are unable to participate in decisions about services.[10] The process of arranging services may differ for people with dementia because such people (unlike many nondemented elderly people) often are not able to assist with the arrangements. It also may be more difficult to find services for people with dementia or to select an appropriate service provider. Since people with dementia are often unaware that they need help, they may be more likely than people without dementia to refuse needed services. Lastly, the process of monitoring and evaluating services may be more difficult if the individual receiving the services is too confused to report problems with the services.

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[10] The problems involved in determining the decisionmaking capacity of individuals with dementia and making decisions about services for people with dementia who are not capable of making decisions for themselves are discussed in ch. 4.

To explore the question of what is different or special about case management for people with dementia, OTA contracted for an exploratory study that involved interviews with case managers in five Pennsylvania AAAs and family caregivers, most of whom had interacted with the AAA case managers (934). The results of the study are discussed in the following section.

Findings From an Exploratory Study of Case Management for People With Dementia

In 1988, a study was conducted for OTA in Pennsylvania to learn about:

- case managers' views regarding the unique aspects and difficulties of working with people with dementia and their families, and
- family caregivers' views regarding the process by which case managers arrange services for their relative with dementia (934).[11]

The study was done in four counties in central Pennsylvania and involved in-depth interviews with 15 staff members from five AAAs and 46 family caregivers of people with dementia, most of whom had received some services through one of the AAAs (934). The 15 AAA staff members who were interviewed for this OTA study included the case management supervisor and two other staff members selected by the supervisor at each AAA; the staff members selected by the supervisors included eight case managers and two case aides. All 15 AAA staff members are referred to as "case managers" in the following discussion.

The AAAs in Pennsylvania provide some services directly or through contracts with other agencies. Elderly people who come to an AAA in need of services are generally evaluated by a case manager, who may then arrange the services for them. If they are not eligible for the AAA's services or if they need services the AAA does not provide, the case manager refers them to other agencies.

Case managers in Pennsylvania's AAAs do not necessarily perform all five case management functions for all their clients, and the AAA case managers interviewed for this OTA study interacted with some of their clients only briefly to determine eligibility or refer them to other agencies. In that sense, they were not always providing case management. Moreover, some of the family caregivers the case managers interacted with may not have needed case management. The observations of the case managers and the family caregivers are instructive, however, with respect to the question of what is special about working with and arranging services for people with dementia.

The samples of case managers and family caregivers who were interviewed were both samples of convenience, not representative groups, and thus allow for a preliminary (rather than a definitive) inquiry into questions about working with and arranging services for people with dementia. The case managers did not know which family caregivers were interviewed for the study. When they spoke about families of people with dementia, they were reflecting on their entire caseload, and their comments do not refer specifically to families that were interviewed.

Perceptions of the Case Managers

The interviews with the case managers were based on a questionnaire designed to elicit information about the types and adequacy of services provided for people with dementia and problems case managers confront in working with and arranging services for people with dementia and their families[12] (934). Although discussions with the case managers inevitably turned to the limited availability of needed services, the primary focus of the interviews was the linking process.

The Types and Adequacy of Services Provided for People With Dementia.—Most of the case managers said that *some* of the needs of people with dementia are being met (934). They indicated a need for more respite services and more in-home personal care. Another problem noted in some counties was the insufficient availability of nursing homes and board and care facilities able to manage patients with disruptive behavior. A third problem noted by some of the case managers was transportation. They said that although people with dementia often need transportation—e.g., to a doctor's appointment—the existing transportation services are not appropriate for them because no escort is provided, and the patient could get lost, forget why he or she was out, or encounter other difficulties.

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[11] A complete report of the OTA-commissioned study in Pennsylvania is available from the National Technical Information Service in Springfield, VA (see app. A).

[12] To ensure that the case managers had a uniform set about what was meant by dementia, they were told that the researchers were interested in their "memory-impaired" clients. "Memory-impaired" was defined as having a diagnosis of Alzheimer's disease or dementia and/or significant functional impairment due to cognitive deficits.

Even with existing resource constraints, some case managers showed considerable ingenuity and persistence in stretching limited resources to the maximum (934). One case manager commented:

> There's a huge gap between what is needed to maintain someone in the community and when they need nursing home care. We patch and bandaid, and people see it as a lifeline and are glad for it (934).

Unique Aspects and Difficulties of Working With People With Dementia and Their Families—Several general themes emerged in case managers' comments about working with people with dementia and their families (934). First, the case managers unanimously agreed that working with people with dementia and their families takes more time and effort than working with other clients. Second, the case managers indicated a need for more flexibility in their jobs to work effectively with dementia clients. They said they need to be able to take the person to a service program for the first time, to be present when an aide first comes into the home, and to take clients to the doctor, drug store, or other places. These kinds of assistance may be needed even for clients with a supportive family, since the family is not always available.

Problems in Working With People With Dementia Who Live Alone—The case managers said that many people with dementia who are served by the AAAs live alone and have no family or other caregiver to help them (934). They noted several ways in which working with these patients is difficult. One problem is getting the patient to recognize his or her need for help and to accept services. They also pointed out that assessment is difficult if a reliable informant is not available at the initial assessment. One said:

> You have to call other people if the pieces of the dementia patient's story don't fit. You have to put a puzzle together. Call a daughter. Find out who else is involved. To determine eligibility, you have to hunt for papers. Finding information takes time (934).

The case managers said that people with dementia usually cannot make arrangements for services themselves or remember arrangements that are made for them. One case manager noted:

> When they need SSI or other benefits or services, they can't do it for themselves. They couldn't handle the phone calls or remember the details (934).

Case managers said that people with dementia who live alone are often fearful and suspicious. One said that she calls clients with dementia before a service provider is scheduled to arrive: "I make them aware someone else is coming to provide the service, and it's not me who will be coming out. A lot of them are skeptical and have been taken advantage of (934)."

Another case manager described how she works with a confused client who lives alone and has no family:

> To get in to see her, I told her I was from the senior center, not the agency. That seemed to help establish trust at first. She doesn't really know who I am or where I come from, but she thinks I'm a godsend. We go from problem to problem with her. I take care of one need, and then wait for a new problem to arise (934).

A third case manager told about a case of hers that illustrates the difficulty of working with someone who cannot report his or her problems (934). The client lived alone in a senior housing facility. Her personal hygiene was sometimes a problem, but the case manager did not think to check her feet. One day, a home health nurse visited the client for other reasons and found the woman's toenails had curled around and were growing into the bottom of her feet. The case manager had taken her to the doctor a week earlier, but the doctor did not check her feet either. A nurse comes to the senior housing facility once a week but stays in her office, waiting for people to come to her. As the case manager noted, confused residents cannot remember when the nurse is there and often fail to report problems, as happened in this instance.

Some case managers were clearly more comfortable than others working with dementia patients who live alone, and they seemed to do it well (934). They would find an entree, establish a relationship and give the client reminders rather than expecting him/her to remember. The case managers who appeared successful with this task also tended to view it as a challenge in which they would somehow piece together a service program from the patchwork of available services. Sometimes this task involved bending procedures a little, and it always involved spending more time with the person than with other clients.

Problems in Working With Families of People With Dementia—The case managers said that families of people with dementia often wait until a crisis to seek help (934). At that point, the family may be too desperate to wait for services, or the available services may be insufficient to meet the patient's and family's needs. One case manager said:

> A lot of times, the family has burned out before we get the referral. They want us to do everything. They want someone to come stay with the patient, help with bathing, or do the finances. Families don't give us the time to work out all these things, though we could do it (934).

The case managers cited many of the same reasons discussed earlier in this chapter as to why families wait until a crisis to seek help, e.g., families believe they should "care for their own," they do not want to leave their relative with strangers, and they feel guilty about using services (934). The case managers also said that some families are deterred from seeking help because the patient denies needing help or resists when it is provided.

Although most of the case managers noted families' reluctance to seek help, two case managers reported that families of people with dementia were more eager than the families of other elderly clients to use services (934). One case manager said:

> Families are anxious, stressed, overwhelmed, scared. They will seek out help more readily than families of physically disabled (934).

According to the case managers, the amount of stress experienced by families of people with dementia contributes to the difficulty of helping them (934). This problem is exacerbated, of course, when families wait until they are at the end of their rope to seek help.

Some case managers distinguished between families who are already involved with the patient and families who are drawn in reluctantly (934). In their view, reluctant families become involved only when the situation has gotten so serious it cannot be ignored, or when they are told to get involved by someone else, such as the patient's doctor, neighbors, or the AAA. Often they are particularly reluctant to get involved if doing so would require managing the patients' finances or placing the patient in a nursing home. The case managers said reluctant families are difficult to work with because they often do not follow through on treatment plans.

Several case managers commented on some families' fear that agencies will take control of the patient (934). One said, "There is a fear of agencies, that they may pull the elder out of the home." Another said, "They fear I will take over, and I won't." This issue of control arose again strongly in the interviews with families.

Some case managers raised another issue that was difficult for them in working with families of people with dementia—that the families persisted in providing care at home beyond what the case manager or physician felt was appropriate (934). Four case managers referred to families' refusal of nursing home placement in these circumstances as "denial" and saw their role as breaking down the family's denial and arranging nursing hone placement. They put more emphasis on that activity than on arranging services for home care. OTA's contractors concluded that these case managers were doing what they felt was in the patient's and family's best interest. The case managers felt that some families were coping with intolerable caregiving situations and that too few services could be provided to support continued caregiving at home.

Other case managers saw their role as doing what they could to support home care (934). They provided information about and assisted with nursing home placement, but they wanted families to make the decision about placement, except in cases of clear danger to the patient.

Perceptions of the Family Caregivers

The 46 family caregivers interviewed for the study in Pennsylvania included some caregivers who were identified by the AAA case managers and some who were recruited independently (934). The primary sources of the independent sample were support groups, an adult day program, and other sources. Despite these sources, it turned out that all but two of the caregivers had been in contact with and received at least minimal assistance from an AAA.[13]

All the caregivers were contacted by an interviewer who explained the study and arranged an interview (934). Interviews were conducted in the family's home or the patient's home if they lived separately. There were very few refusals.

The mean age of the patients whose caregivers were interviewed was 77 years (934). Thirty-six of the patients were living at home; 9 were living in a nursing home or board and care home; and 1 had just died. All but four of the patients had a diagnosis of Alzheimer's disease or another dementing disease, and in those four cases, the patient's history and functioning were consistent with dementia.

The mean age of the 46 caregivers was 55. Eighteen of the caregivers were spouses of the patient; 20 were daughters or daughters-in-law, and 8 were other relatives (934). Duration of caregiving averaged 4 1/2 years, with a range of 3 months to 14 years. Nineteen of the 46 caregivers (41 percent) said they had someone they could count on as backup caregiver, whereas 27 (59 percent) said they did not have a backup caregiver.

Sources of Information About Services—The caregivers said they most often learned about formal services from the AAA, physicians, and other family members (934). When asked whom they would turn to for more information, caregivers noted the AAA most frequently. Many caregivers said the patient's doctor did not refer them for case management or for home care. Most physician referrals apparently were for nursing home care.

Overall, about half the family caregivers said they had received enough information about services, and half said they had not. Forty-one caregivers (89 percent) said it would be extremely or very helpful to have a central source of information about services.

Use of and Satisfaction With Formal Services—The caregivers reported using various kinds of services, including personal care (22 families), respite care (14 families), and adult day care, homemaker, legal and financial services, and home-delivered meals (11 families each) (934). They generally were satisfied with the services they were using. Almost unanimously, however, they said they could use "a little more help." Sometimes, "a little more" was a global understatement of the desperation the caregivers felt, but in other cases, it meant that a little assistance—an occasional phone call or a couple of hours of respite a week—would go a long way.

Despite their general satisfaction with services, some caregivers complained about respite and personal care workers who did not show up or were poorly trained (934). Many of the caregivers also complained about the inflexibility of the service system. They were upset about not being able to schedule helpers at a convenient time or specify a particular worker. They complained about the lack of services on evenings and weekends and about services that excluded patients with behavioral or emotional problems or severe functional impairments.

As a result of these difficulties, many caregivers were frustrated (934). Some dropped out of the service system altogether and used no services. A few hired home health aides privately. Others said they learned how to work with agencies to get what they wanted. One caregiver said that she had gone through three home health agencies and 10 nurses whom she thought were not adequate. She now has worked out an arrangement with a home health agency so they send only their better trained nurses.

The caregivers said that they could accept services more easily if the services were therapeutic, not just "babysitting (934)." Moreover, like the caregivers who received services from the Duke respite care demonstration project, many of these caregivers said they had difficulty accepting services if the focus is on their needs and that they could accept services more easily if the services are for the patient. Many of the caregivers did not see a connection between their own physical and psychological well-being and their ability to continue caring for the patient.

Interactions With AAA Case Managers—As mentioned earlier, all but 2 of the 46 family caregivers in this study had had at least some contact with an AAA (934). The caregivers' overall satisfaction with all these interactions was quite high. One caregiver, a 53-year-old woman who was caring for her mother-in-law with Alzheimer's disease, said:

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[13] This finding should not be interpreted as indicating that most families are in contact with an AAA or are receiving services from an AAA; the result is probably a function of the sampling method, since people who attend support groups or a day care program are likely to use other services (934).

> The AAA is the best link for help with the elderly. We have been well pleased. We recommend them to anyone with an elder. They can link you up to all the help that is out there. They are concerned, they follow-up, and they do their homework (934).

Another caregiver, a 63-year-old woman who had taken care of her mother with Alzheimer's disease until the mother was placed in a nursing home, also was very pleased with AAA case management. The primary assistance she received was an assessment and help with nursing home placement. She said:

> The AAA returned calls, the staff was compassionate and helpful. They gave us time. They didn't make us feel unimportant or an imposition (934).

Despite the caregivers' generally positive attitudes about AAA case management, they did note several problems (934). Caregivers complained about overly bureaucratic procedures, particularly when steps they considered unnecessary were required in order to arrange services. For example, one caregiver felt she received a "runaround" when scheduling respite services that were already authorized by the AAA case manager. She said she first had to call the case manager, who then called the agency providing the services. In her view, this process led to additional slipups. She said she would have preferred to arrange the services herself. Other caregivers agreed. When asked, "If someone were available to arrange services, who would you prefer that person to be?" 12 caregivers (26 percent) said they would prefer to do it themselves; 29 (63 percent) said an agency should do it; 3 (7 percent) said both; and 2 (4 percent) named other alternatives.

One caregiver, a 33-year-old woman who had been caring for her mother-in-law for 14 years, said that the critical factor in case management is having someone to talk to (934). She said the AAA case manager had helped her by spending time with her, allowing her to talk out some of her frustrations, but that she would have preferred to arrange services herself.

Some of the caregivers understood the process by which AAA case managers authorized and arranged services, but most did not (934). Several said they did not know how they were identified to receive help in the first place. They said someone from the AAA "just showed up one day," or they received a letter saying they were eligible. One caregiver said he felt the AAA came in almost surreptitiously, without involving him. Some said they did not understand how benefits were determined, but they did not want to ask because they were afraid of losing the services they were receiving.

The primary concern of caregivers was not case managers, however, or the positive or negative aspects of the case management process. For them, the bottom line was services (934). Several caregivers were angry at the AAA case manager or the AAA because of policies that denied them services they needed. OTA's contractors in Pennsylvania reported the following example:

> One 49-year-old widow was taking care of both her 87-year-old mother with dementia and a severely disabled 29-year-old daughter. The mother was attending a day care program, which the caregiver liked. She also got some in-home help for her daughter. She used this help to care for both her mother and daughter but felt that doing so was unfair to the helper. Because of an AAA policy, she was not able to get any in-home help for her mother as long as the mother was in the day care program. She did not understand this policy and was very angry with the AAA (934).

An important aspect of satisfaction for caregivers was having a relationship with someone in the service system who would give them emotional support and help them navigate the system (934). For some caregivers, this person was the case manager; in many cases, however, it was someone else, e.g., the person who delivered meals to the home or the aide who provided personal care. To the caregivers, having an advocate in the system seemed to make the difference between getting what they needed or giving up. OTA's contractors noted that such a relationship seemed more important for less educated and less sophisticated caregivers.

Implications for an Effective System To Link People With Dementia to Services

The overriding consensus of the 15 case managers in the Pennsylvania AAAs was that working with and arranging services for people with dementia is more difficult and more time-consuming than working with and arranging services for their other clients (934). Many people with dementia deny their need for services and refuse services. They cannot provide information or remember arrangements that have been made for them. Some are fearful and suspicious. Case managers need special skills to work with these patients. Problems that arise in working with families of people with dementia—particularly

Photo credit: Alzheimer's Association and Rush-Presbyterian/St. Luke's Medical Center

Case managers need special skills to work effectively with people with dementia and their families.

problems related to the tendency of families to hold back from seeking services until the situation is desperate—also may require special skills.

Judging from examples the AAA case mangers gave, OTA's contractors concluded that some of the case managers dealt with people with dementia and their families in very skillful ways (934). The case managers had received no formal training for this ability, however. Given the difficulty of providing case management for some people with dementia and their families, it is reasonable to suggest that case managers need special training to work effectively with these patients and families.

The majority of the 46 family caregivers interviewed for the study in Pennsylvania were satisfied with the services they had received and with their contacts with the AAA case managers (934). Their primary concerns were that not enough help is available and that the quality of personal care and respite services is sometimes poor.

Another concern of the family caregivers was control (934). Caregivers want to have control over services, particularly in-home services. They want to have some say as to when services are provided and who provides them. A lot of resentment was directed at the AAAs for not allowing families to request a particular nurse or aide. They also were angry when bureaucratic procedures resulted in services not being delivered. One-fourth said they would rather arrange services themselves than have a case manager act as an intermediary.

OTA does not know whether families of people with dementia are more likely than families of nondemented elderly people to want to retain control over services and how the services are provided. It is possible that families of people with dementia become more protective than families of nondemented people in response to the diminishing ability of the dementia patient to plan or advocate for himself or herself. In any event, a recognition of families' desire to have control over services should be built into the case management component of a system that links people with dementia to services.

One aspect of control is understanding the rules of the game—in this context, how eligibility is determined and services are authorized (934). Many of the family caregivers interviewed for the study in Pennsylvania were mystified about how the level of service was determined or why they received help at all. This lack of understanding undermines their sense of control. In the view of the advisory panel and contractors for this OTA assessment, an important objective of case management with families of people with dementia is to help them understand the basis for decisions about services so as to increase their sense of control.

Finally, some case managers interviewed for the study regarded the more impaired dementia patients as needing institutionalization, regardless of the their families' wishes (934). They believed that the families could not continue to provide adequate care and that available services were not sufficient to supplement the families' efforts. Other case managers made extensive efforts to support home care, even when services were limited, if that was the preference of the family. These differences in approach were due to several factors, including how comfortable case managers were in working with people with dementia and the advice they received from "experts," including one geriatric assessment team that frequently urged nursing home placement.

In the interactions of health care and social service professionals, case managers, and families, the issue of when institutionalization should occur is often couched as a professional or even medical decision. Except in cases where there is abuse or neglect, however, the timing of institutionalization is probably more appropriately and realistically viewed as a question of individual values and perceptions. Some families are willing to make tremendous sacrifices to keep a relative at home, and, as discussed earlier, some apparently do not perceive objectively difficult caregiving situations as overwhelmingly burdensome. It is probably inappropriate for case managers to regard these enduring caregivers as neurotic or to label their feelings as "denial." That some caregivers have conflicted motives is obvious; they may also have sincere and profound beliefs about what they are doing. They often continue home care despite intense pressure to institutionalize from doctors, service providers, and other family members. If a case manager pushes family members to institutionalize their relative, they may withdraw from the service system completely and consequently receive no services (934).

It is the opinion of OTA's contractors and the advisory panel for this study that except in cases of abuse or neglect, case managers should inform family caregivers about all their options, including nursing home placement, and allow them to make the decision. The question of what constitutes sufficiently poor family care to trigger a decision to institutionalize a dementia patient over the objections of his or her family requires further analysis.

UNRESOLVED QUESTIONS ABOUT CASE MANAGEMENT IN A SYSTEM TO LINK PEOPLE WITH DEMENTIA TO SERVICES

Although OTA has concluded that case management is an essential component of an effective system to link people with dementia to services, many questions remain to be answered about case management in such a system. Several of these questions are discussed further below:

- To what extent should a linking system try to maintain at home individuals with dementia who live alone and have no informal caregiver?
- Should counseling be part of case management in a linking system?
- In general, should families be regarded by a linking system as "co-case managers" or "co-clients"?
- How many people with dementia need case management?
- How much would case management in a linking system increase the use of services?

The answers to these questions have implications for the design and operation of the case management component of a linking system and for the job description and skills of case managers employed by the system.

To What Extent Should a Linking System Try To Maintain at Home Individuals With Dementia Who Live Alone and Have No Informal Caregiver?

At least 20 percent of people with dementia live alone, and as many as half of them have no informal caregiver to assist them (see ch. 1). In developing a system to link people with dementia to services, it is important to decide how the system should respond to these individuals, who may require a lot of involvement on the part of a case manager if they are to remain in the community.

People with dementia who live alone and have no informal caregiver are at risk for injuries and other problems. Some home health care agencies will not accept them as clients because the agencies do not want to be liable for problems that occur when the individuals are alone (239). One question in developing a linking system is the degree of risk to an individual that can or should be tolerated, but that risk needs to be weighed against problems people with dementia encounter in institutional settings. A related question is what liability the linking system or its case managers would incur for people with dementia who live alone, have no informal caregiver, and are maintained at home with intermittent services and supervision by a case manager. Both questions require further analysis.

The case managers in the study conducted for OTA in Pennsylvania said that providing services that are not ordinarily considered case management—e.g., taking a client with dementia to a program the first time, being in the person's home when a new aide arrives, or driving the person somewhere if no other source of transportation is available—is sometimes essential in implementing a client's plan of care (934). Such services are especially likely to be needed for people with dementia who live alone and have no informal caregiver. Sometimes, a case manager can arrange to have these services provided by a volunteer or a paid chore worker. But what if that is not possible and the case manager judges that failure to provide the services could cause a major disruption to the client's already precarious functioning? Should case managers employed by a linking system provide the services themselves?

Some private geriatric case managers who are hired by patients or families to provide case management provide services that are peripheral to case management but may be essential to supporting the patient and maintaining the patient's independent functioning. A 1986 survey of private geriatric case managers conducted by Interstudy found that 16 percent of the 117 respondents provided transportation; 16 percent provided homemaker services, and 11 percent provided chore services (357). In some cases, however, the services were provided by case aides or other support staff members who worked with the case manager.

Some case managers also make themselves available to their clients at any time for emergencies. Eighteen percent of the private geriatric case managers who responded to the Interstudy survey just cited said they provided a 24-hour hotline (357). Some public and private case management agencies also provide a 24-hour hotline (746). One private geriatric case manager, speaking to a National Council on the Aging symposium on case management, told about an instance in which one of her clients, an elderly woman with dementia who was living alone, became very confused in the middle of the night. Ordinarily, a paid homemaker helped the woman get ready for bed before she left for the evening. On this particular night, the usual routine was not followed for some reason. The woman with dementia became agitated and called a friend, who then called the case manager. The case manager went to the woman's house, helped her get into her nightgown, and waited until she fell asleep to leave (136).

OTA does not known whether instances like this occur more often in the case of individuals with dementia than in the case of other individuals receiving case management, but such instances do raise questions about the appropriate role and functions of case managers. If the occasional provision of "non-case-management" services enables case managers to maintain at home clients with dementia (and perhaps other clients) who live alone and have no informal caregiver, should a linking system build into the case managers' job description sufficient flexibility to allow them to provide such services? Alternatively, should case aides of some sort be available in the system to provide the services at the direction of the case manager? These questions remain to be answered.

Should Counseling Be Part of Case Management in a Linking System?

In the context of a linking system, counseling is most likely to be needed for caregivers who do not use services because they feel guilty about accepting help, fearful that others will disapprove of their use of services, ashamed of the patient's behavior, reluctant to make decisions for the patient, or simply too overwhelmed by various feelings to think clearly about solutions to their problems. Counseling also may be needed when family members disagree about the patient's care and what services are appropriate. Lastly, counseling may be needed for some patients who are reluctant to use services, although in many cases the effectiveness of counseling for patients is problematic.

It is unclear whether counseling should be part of case management in a linking system or whether patients and their caregivers who need counseling should be referred by the linking system to other sources of counseling. If counseling is to be provided by the linking system, however, the individuals hired as case managers by the system must have the necessary education and training to provide it.

In General, Should Families Be Regarded as "Co-Case Managers" or "Co-Clients" by a Linking System?

Families of frail older people frequently perform case management tasks themselves, acting as intermediaries between the older person and formal service providers (85,92,110,467,477,753,778). Some commentators have suggested that maximizing a family's performance of case management tasks might increase the family's satisfaction with services, meet patients' needs more appropriately, minimize costs, and eventually decrease the need for a paid case manager (271,753,754,758). Despite this suggestion, few attempts have been made to help families become better case managers (175).

One project did train and assist some families of elderly people (including some families of people with dementia) to perform case management tasks, such as arranging and monitoring services (753,754,758). Together, a social worker and a family member developed a "case management service plan" that allocated case management tasks between them. Family members were given information about community resources, and the social worker contacted them at least every 2 weeks to answer questions, monitor their performance of case management tasks, and provide supportive counseling. The results of the project showed that the families who received the training and assistance accomplished significantly more case management tasks than did a control group of families that did not receive the training and assistance. Additionally, the total duration of services was significantly shorter for the older people whose families received the training and assistance than for older people whose families did not (753).

Interestingly, whether families received this training and assistance was not the largest predictor of their performance of case management tasks. The largest predictor was the cognitive status of the patient. For both the experimental and control groups, families of people with dementia were more likely than families of other individuals to perform case management tasks (753).

A linking system could regard families primarily as "co-case managers" and attempt to maximize families' performance of case management tasks by providing training and assistance to help them perform the tasks successfully. Alternatively, a linking system could regard families primarily as part of the client unit, or "co-clients," whose needs are assessed along with the patient's needs and incorporated into the patient's care plan. Families differ, of course, and whether a specific family is most appropriately regarded as a co-client or a co-case manager depends on the characteristics of the family and the caregiving situation. The presumption of the system—i.e., whether the system generally regards families as co-case managers or as co-clients—is likely to affect how comfortable families are with the system. Certainly, at least some families of people with dementia would prefer to be regarded as co-case managers than as co-clients, because the role of co-case manager would allow them a greater degree of control over services that may be used for their relative with dementia.

Even if a linking system generally regarded families as co-case managers, some families would be more appropriately treated as co-clients. Determining which families could function successfully as co-case managers (with or without training and assistance) and which families should be treated as co-clients would require difficult judgments by case managers in at least some instances. To make these judgments and to help families become better case managers would require special skills on the part of the case managers employed by the linking system.

How Many People With Dementia Need Case Management?

Although OTA has concluded that case management is an essential component of an effective system to link people with dementia to services, an important question that remains to be answered is how many people with dementia need case management. Most people would probably agree that people with dementia who live alone and have no informal caregiver to help them all need case management—at least at the point when they become unable to plan for themselves or manage their affairs independently (a point that to some extent rests in the eye of the beholder).

A somewhat more difficult question is how many people with dementia who *have* an informal caregiver need case management. As noted in the previous section, families often perform case management tasks for elderly people, including people with dementia. If accurate information about services and funding for services were readily obtainable, more families and other informal caregivers would be able to arrange services themselves, and fewer people with dementia would need case management. If training and assistance were available to help families and other caregivers perform case management tasks, as suggested above, still more caregivers would be able to arrange services themselves. On the other hand, some family caregivers have intense feelings that still would make it difficult or impossible for them to arrange services themselves, as illustrated in one woman's description of the process of placing her husband in a nursing home:

> Finally the dreaded conclusion was reached that he had to go to a nursing home. No one can imagine the devastation I reached at this time. But it had to be done, so I had to find a way to cope. At the time of transition to the nursing home, the most important help I received was from the social service worker. She made phone calls and gathered and gave me information. There was nothing easy about it, but she was a real buffer (670).

The woman just quoted probably could have made the phone calls and arranged for her husband's admission to a nursing home herself if she had not been so upset. There are also situations in which the informal caregiver of a person with dementia is almost as impaired as the patient and is totally incapable of arranging services. In both types of situations, most people would probably agree that case management is needed for both the caregiver and the person with dementia.

The advisory panel for this OTA study was unanimous in the view that *not all people with dementia who need services also need case management*. The panel particularly rejected the idea that all family caregivers need a case manager to help them define their service needs. While recognizing that some caregivers need help to define their service needs, panel members pointed out that many family caregivers can define service needs themselves.

In apparent conflict with the advisory panel's view that not all people with dementia who need services also need case management, many of the congressional proposals to provide expanded long-term care services that were introduced in 1988, 1989, and 1990 (100th and 101st Congress) specify that everyone who received the expanded services would also receive case management. Under these proposals, even people who have informal caregivers who are (or believe they are) capable of defining their needs and arranging and monitoring services themselves would receive case management. The case management in the congressional proposals generally includes both ''administrative'' tasks (e.g., authorizing services in accordance with program regulations) and ''clinical'' tasks (e.g., helping people define their service needs and select appropriate services in their communities).[14]

One way for Congress to address this apparent conflict would be to conclude that case management is, in effect, the price of receiving long-term care services and to assume that caregivers and others will be willing to accept case management to get the services—probably a reasonable assumption in most cases. Case management is an expensive addition to the cost of services, however (105,114). For that reason, Congress might prefer to limit the case management that is required for everyone to those administrative tasks that are essential to allocate services in accordance with program regulations, and to require or allow case management beyond those administrative tasks only for people who are identified as needing them by some specified criteria.

As noted earlier, the term ''case management'' means different things to different people. Thus, various commentators' views about whether case management is needed in certain contexts or for certain types of people may or may not refer to the same ''case management.'' In addition, although a major purpose of case management is to help people obtain the services they need, ideas about what case management is and who needs it have come almost exclusively from academics, administrators, policy analysts, and case managers—not from people who might need or use it. When people who might need or use case management are asked, their opinions about case management are quite different from the ideas of those other individuals, as illustrated by findings from several studies and a fee-for-service case management program discussed below. The discussion below is not comprehensive, nor is it intended to suggest that the ideas of people who have used or may use case management are necessarily correct about what case management is and who needs it and that other people's opinions on these topics are incorrect. Rather the discussion is intended to highlight certain opinions of current and potential users of case management that are relevant to the questions of how many people need case management and how many might use it.

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[14] The distinction between case management as an administrative process in which the case manager is primarily responsible for allocating services in accordance with program regulations and case management as a clinical process in which the case manager functions more as a professional helper and advocate than as an administrator of services was discussed earlier in this chapter.

Some insight into people's opinions about case management can be derived from the findings of market research conducted for the Robert Wood Johnson Foundation's Supportive Services Program for Older Persons. The research indicates that many older people and their caregivers do not understand what case management is or why they might need it (318). The Supportive Services Program for Older Persons is intended to demonstrate the feasibility of developing a private market for in-home and community services and to design a package of such services that people will purchase. The first phase of the Supportive Services Program involved market surveys in 13 localities to determine the demand for services of various kinds. The market surveys found that elderly people and their caregivers have three problems with case management:

- They do not see themselves as "cases" to be managed.
- They do not understand why they would need a special person or a special set of functions in order to obtain services.
- They do not understand why they should pay for something that, in the private sector, might be viewed as customer service or public relations (318).

Many people who were contacted for the market surveys expressed confidence in their ability to define their own service needs and did not think they would need a case manager to help (91).

Case management generally is perceived by academics, administrators, policy analysts, and case managers as a series of interrelated steps that constitute a logical problem-solving process that is directed by a case manager. The results of interviews conducted for OTA with 46 family caregivers of people with dementia in Pennsylvania suggest that the caregivers had different perceptions about case management. For example, there is no evidence from the interviews that the caregivers perceived case management as a logical problem-solving process or that they regarded the case manager as the central figure directing that process (934). Family caregivers who were looking for services used various sources of information and assistance. Some of them relied less on a case manager for help in negotiating the service system and obtaining needed services than they relied on an in-home aide, a volunteer who delivered meals, or the director of an adult day care program. These caregivers saw themselves, rather than the case manager, as directing the case management process.

The experiences of Connecticut Community Care, a private case management agency, suggest that people often want only certain case management functions. Connecticut Community Care has been providing case management for publicly funded long-term care programs for some time and began offering fee-for-service case management in 1986 (75). The agency markets a comprehensive case management service that includes all the case management functions discussed earlier in this chapter, plus counseling, but people often purchase single case management functions—e.g., client assessment or service coordination. Many of the agency's case managers have been uncomfortable with splitting up what they perceive as interrelated case management functions—separating client assessment from care planning, for example, or care planning from service arrangement.

Connecticut Community Care's fee-for-service case management is controlled by the client, not the case manager, and many of the agency's case managers have been uncomfortable with their loss of control (75). Despite that feeling, the case managers have been pleased with the flexibility they have in responding to these clients' needs and with some of the positive outcomes they have seen. The agency's fee-for-service clients have been happy with the case management services they have purchased.

The results of the Robert Wood Johnson Foundation's market research, the interviews with family caregivers conducted for OTA in Pennsylvania, and Connecticut Community Care's experiences with fee-for-service case management suggest that different people want and need different kinds of help with defining their service needs and selecting, arranging, and monitoring services. An underlying theme, however, is that people perceive themselves as being in control of the linking process and that they want to retain that control.

The American Nurses' Association, the National Association of Social Workers, the National Council on the Aging, and other commentators state that the primary goals of case management include empowering people, increasing people' sense of control over their own lives, and helping people attain their own objectives (22,48,572,581,893). Achieving these goals is difficult in a complex, fragmented service environment in which resources are limited and the services people want are sometimes unavailable or too expensive—and the difficulty is probably compounded when a person is cognitively impaired and the person's caregiver is unsure of what he or she wants or is ambivalent about using services at all. The difficulty is probably further compounded when the case manager is responsible to an agency for a series of administrative procedures to authorize and account for the use of resources.

If the objectives of a linking system include empowering people, increasing their sense of control, and helping them achieve their own objectives, several requirements must be met. First, there must be a clear recognition that these are objectives of the system. Second, there must be guidelines for implementing them, and third, there must be training for case managers to help them achieve the objectives.

How Much Would Case Management Increase the Use of Services?

The extent to which case management would increase the use of services probably depends in part on whether the case manager has funds and authority to purchase services for clients or just arranges services for them. The National Long-Term Care Channeling Demonstration compared use of services by elderly people in three groups:

1. a "basic case management group," in which a case manager had only limited funds to purchase services and primarily brokered available services for the clients;
2. a "financial control group," in which a case manager had funds and authority to purchase services for the clients; and
3. a control group, in which the clients received no case management or services through the project (although some clients received case management and/or services from other sources); (147).

Elderly people in the basic case management group, in which the case manager primarily brokered services, were using 11 percent more in-home services than the control group after 6 and 12 months and 6 percent more in-home services after 18 months (147). Elderly people in the financial control group, in which the case manager had funds and authority to purchase services, were using 22 percent more in-home services than the control group after 6 months, 18 percent more in-home services than the control group after 12 months, and 14 percent more after 18 months. Thus, basic case management without funds to purchase services increased service use by 6 to 11 percent over the use which would have otherwise occurred, while case management with funds and authority to purchase services increased service use twice that amount.

The results of a recently completed respite service demonstration project conducted by the Philadelphia Geriatric Center (88,448) also show that case management with funds to purchase services increased service use, but overall use was still lower than one might have expected, given caregivers' expressed need for respite services. The project made respite services available to family caregivers of Alzheimer's patients through a case management process. The caregivers who volunteered for the project received an initial assessment and were randomly assigned to a control or experimental group.

Caregivers in the control group were given a list of local service providers and were reassessed at the end of the study, a year later. Caregivers in the experimental group were offered respite services to be provided in their home, in an adult day center, and/or in a hospital or nursing home (88,448). A case manager was available to help the caregivers identify their needs, to develop a care plan, to assist in arranging respite or other services, and to provide counseling to help caregivers with problems that might interfere with their use of services. Interactions between the case managers and the caregivers in the experimental group varied. The caregivers were contacted at least every 2 months; in some cases, contact was much more frequent.

As noted earlier in this chapter, only about half the caregivers in the experimental group in this study used any respite services over the course of the year

(88,448). Thirty-five percent used in-home respite; 2 percent used adult day care; 7 percent used overnight nursing home care, and 8 percent used more than one kind of respite care. Moreover, most of the caregivers who used respite care used very little of it. Even though the case managers encouraged the use of respite services, therefore, overall use of the services was still low. According to the researchers, some caregivers were so emotionally invested in their role as caregiver that they were unable to accept any services, even with extensive counseling and support. Other caregivers only slowly came to understand the concept of respite care and might have begun to use respite services if the demonstration project had continued beyond the 1-year period.

A comparison of the experimental and control groups at the end of the respite service demonstration project showed that the project intervention—i.e., the case management, the offer of respite care, and the respite services that were used—had no significant effect on caregivers' attitudes, perception of burden, or self-reported physical or mental health (448). The project intervention did have a significant effect on the number of days that patients remained in the community (447). Dementia patients whose caregiver was in the control group were institutionalized or died an average of 22 days sooner than dementia patients whose caregiver was in the experimental group. Interestingly, this difference was not between caregivers who used respite services and those who did not. Rather, it was between caregivers who received the whole intervention—case management, counseling, education, the offer of respite, and any respite services that were used—and caregivers who did not. The researchers suggest that the whole intervention, including the knowledge that respite services would be available if needed, that "constituted a strain-reducing influence that fortified caregivers in the experimental group in their resolve to defer institutionalization as long as possible" (447).

CONCLUSION

Some people with dementia and some caregivers have characteristics, feelings, or perceptions that make them reluctant to use services or unable to arrange services themselves. These individuals are unlikely to respond to public education programs and may be unwilling or unable to contact an information and referral source on their own. Some of them do not need services, but many undoubtedly do. These individuals often include some of the most isolated patients and objectively burdened caregivers. Outreach and case management programs are needed to connect these people to services. Although it is unclear how many people with dementia need outreach or case management, it is clear that outreach and case management are essential components of an effective system to link people with dementia to services.

Outreach must be active and individualized to reach isolated people with dementia and isolated caregivers. Some initiatives that often are called outreach, such as lectures to community groups and publicity in various media, are effective in reaching some people with dementia and some caregivers but not those who are most isolated. Individualized approaches are needed for those persons. The gatekeeper model described in this chapter is most likely to be successful in reaching them.

The five core functions of case management identified in table 3-1—assessing a client's needs, developing a plan of care, arranging and coordinating services, monitoring and evaluating the services that are delivered, and reassessing the client's needs—are clearly relevant to many of the characteristics, feelings, and perceptions that keep some people with dementia and their caregivers from using needed services. Clearly, case managers need special knowledge and skills to work effectively with people with dementia. Moreover, some adjustments may be needed in case management procedures to accommodate some—and perhaps many—families' preference and ability to control the process of locating and arranging services themselves.

Finally, it is important to note that neither outreach nor case management can compensate for the insufficient availability of services and funding for services. Outreach programs can find people who need services, and case managers often can piece together services and funding for a client from the fragmented service system, but the services and funding first must exist. Outreach and case management are essential components of a system to link people with dementia to services, but they are not a panacea for all the problems of long-term care.

Chapter 4

Questions That Arise in Making Decisions About Services

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Chapter 4

Questions That Arise in Making Decisions About Services

INTRODUCTION

Linking people with dementia to services involves many important decisions—what services are needed, who will provide them, who will pay for them, and, perhaps most importantly, whether the person will be cared for at home or in a nursing home or other residential care facility. Because of their cognitive impairments, people with dementia generally become less capable of making decisions for themselves. Their diminished decisionmaking capacity[1] raises difficult questions for individuals and agencies involved in linking them to services. This chapter considers two of these questions:

- How should the decisionmaking capacity of people with dementia—in this context, their capacity to make decisions about services—be determined?
- How should decisions about services be made for people with dementia who are not decisionally capable? In other words, who should be the surrogate decisionmaker and what criteria should guide the decisions?

Questions about how to determine whether individuals are capable of making decisions and about how to make decisions for those individuals who are decisionally incapable have been analyzed and debated at length in contexts involving other populations, including mentally ill, unconscious, and terminally ill people, and other decisions, particularly decisions about the use of life-sustaining medical treatments and about participation in research. So far, however, such questions have not received much attention in contexts involving people with dementia and everyday decisions about health care, long-term care, social, and other services that such people may need (93,327).

At the policy level, questions about how to determine demented individuals' decisionmaking capacity and how to make decisions about services on behalf of those demented individuals who are not capable of making such decisions themselves are often obscured by overriding concerns about the lack of sufficient services and funding for services.[2] At the level of individual case managers and others who arrange services for people with dementia, the questions are often obscured by the practical difficulties of locating and arranging services in a complex service environment. They may also be obscured by pressures on case managers to complete service arrangements quickly (e.g., because the client is in an unsafe situation, the client's informal support system is overwhelmed, the case manager has many other clients, or the hospital wants the client discharged "yesterday").

It is important to recognize that although questions about how to determine a demented person's decisionmaking capacity and how to make decisions on behalf of decisionally incapable demented clients are often obscured, such questions are *inherent* in the process of linking people with dementia to services. Whenever the linking process goes beyond public education and information and referral to include the actual arranging of services, these questions are unavoidable.[3] Every individual or agency that arranges services for people with dementia necessarily answers the questions in one way or another—either by following explicit procedures for determining decisionmaking capacity and making decisions on behalf of clients who are decisionally incapable or by making implicit judgments. If Congress mandated a system to link people with dementia to services, the agencies that constituted the system would confront the problems of determining decisionmaking capacity and designating surrogate decisionmakers whenever they helped to select or arrange services for people with dementia.

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[1] As discussed later, this chapter distinguishes between the terms "decisionmaking capacity," "decisionally capable," and "decisionally incapable" on the one hand and the terms "competency," "competent," and "incompetent," on the other. The terms "competency," "competent," and "incompetent" are used only to refer a person's legal status. The terms "decisionmaking capacity," "decisionally capable" and "decisionally incapable" are used to refer to a person's capacity to make decisions in a more general sense. These terms are unfamiliar to many people and their use sometimes results in cumbersome sentence constructions, but OTA believes that these terms are more accurate than other available terms that might be used to represent the concepts being discussed. OTA apologizes to readers who find the terms unfamiliar or their use contorted.

[2] The lack of sufficient services and funding for services is a topic that was addressed in OTA's 1987 report *Losing a Million Minds: Confronting the Tragedy of Alzheimer's and Other Dementias* (831).

[3] The need for a linking system to go beyond public education and information and referral in order to serve certain types of dementia patients and their caregivers is discussed in ch. 3.

Most agencies that link people with dementia to services have no explicit policies or procedures for determining their clients' decisionmaking capacity or for making decisions about services on behalf of clients who are decisionally incapable. In the absence of explicit policies and procedures, case managers and others who arrange services in these agencies must act on their own judgments about whether their clients are capable of making decisions about services and about how such decisions should be made for clients who are not decisionally capable. Some of these case managers and others may not be aware of the implications of these judgments, and some of them may not even be conscious of making the judgments.

Judgments about a person's decisionmaking capacity and about how decisions should be made for people who are decisionally incapable involve fundamental legal rights and complex legal and ethical issues, some of which are discussed in this chapter. If an agency, case manager, or other individual that arranges services for people with dementia is not aware of the legal rights and legal and ethical issues involved in decisionmaking, there is little likelihood that those rights and issues will be adequately considered when decisions about services are made.

In the context of linking people with dementia to services, one major objective in determining decisionmaking capacity is to ensure that people who are decisionally capable will be given the opportunity to make decisions about services themselves and that people who are not decisionally capable will be protected from decisions that may be harmful to them. The ultimate objective in designating a surrogate decisionmaker and establishing criteria to guide surrogate decisions is to ensure that the best possible decisions are made for people who are not decisionally capable. Establishing explicit agency policies and procedures for determining decisionmaking capacity and for making surrogate decisions would not guarantee the achievement of these objectives. Nevertheless, establishing explicit policies and procedures could help focus agencies' and case managers' attention on the important legal rights and legal and ethical issues at stake in decisionmaking and thereby increase the likelihood that those rights and issues would be considered when decisions about services are made.

This chapter discusses certain concepts and distinctions that are important in thinking about how to determine people's decisionmaking capacity and how to make decisions on behalf of people who are not capable of making decisions themselves. The chapter also discusses some approaches that agencies and individuals that arrange services for people with dementia might use to determine their clients' decisionmaking capacity and to make decisions about services for clients who are decisionally incapable. Some of the concepts, distinctions, and approaches discussed here are derived from analysis and debate about other types of decisions (e.g., decisions about the use of life-sustaining medical treatments and participation in research) and about other client populations (e.g., mentally ill, unconscious, or terminally ill people), and they may or may not be directly applicable to decisions about services for people with dementia. Other concepts, distinctions, and approaches discussed here are derived from recently completed and ongoing research and demonstration projects that address the problems of decisionmaking for people with dementia more directly.[4]

The chapter discusses many unresolved issues. For some of the issues, there is, as yet, no agreement about the correct theoretical resolution. For other issues, there is agreement about the correct theoretical resolution but little understanding about how to apply it in the context of linking people with dementia to services.

If Congress mandated a national system to link people with dementia to services, it could require that the agencies that constitute the system have explicit policies and procedures for determining their clients' decisionmaking capacity and for making decisions for people who are not capable making decisions themselves. The concepts, approaches, and issues discussed in this chapter are relevant to the content of such policies and procedures and the questions that would have to be answered in developing them.

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[4] These projects include: 1) studies under the "Personal Autonomy in Long-Term Care Initiative" funded by the Retirement Research Foundation (327); 2) a study of hospital discharge planning for elderly people with diminished decisionmaking capacity, funded by the Florence V. Burden Foundation and the Retirement Research Foundation (181,241); and 3) a project funded by the Ittleson Foundation and the Retirement Research Foundation to train "temporary treatment guardians" and to refine and disseminate a "values history questionnaire" that allows individuals to document their preferences and values so that if surrogate decisionmaking becomes necessary in the future, it will reflect the individual's wishes (252,802).

DETERMINING THE DECISIONMAKING CAPACITY OF INDIVIDUALS WITH DEMENTIA

The extent to which individuals with dementia are capable of making decisions about services varies. Some people with dementia, especially in the early stages of their disease, are quite capable of making some or all decisions about services for themselves. Others, in the opinion of everyone who knows them, are incapable of making even simple decisions. Many people with dementia fall somewhere between these extremes.

Under U.S. law, adults are presumed to be competent unless and until factual evidence that refutes the presumption of competency has been presented to a court and the court has declared the person incompetent (945). Adults who have not been adjudicated incompetent have a legal right to make decisions about their medical care, where and how they will live, and how they will manage their own affairs. The vast majority of people with dementia have not been adjudicated incompetent. A 1986 survey of nursing homes in New York State found, for example, that under 3 percent of the homes' residents had been declared legally incompetent (609), even though at least 40 percent of the State's nursing home residents have dementia (217).

Since individuals with dementia who have not been adjudicated incompetent are presumed under U.S. law to be competent, they have a legal right to make their own decisions. Nevertheless, some people with dementia who have not been adjudicated incompetent are, in the opinion of virtually everyone who knows them, incapable of making important decisions about their lives. This chapter uses the terms "competent," "incompetent," and "competency" only to refer to a person's legal status. It uses the terms "decisionally capable," "decisionally incapable," and "decisionmaking capacity" to refer to a person's ability to make decision in a more general sense.

People who make judgments about dementia patients' decisionmaking capacity—physicians, other health care and social service professionals, hospital discharge planners, case managers, service providers, and others—often err by automatically assuming that any person with a diagnosis of a dementing disease is incapable of making decisions and by turning immediately to the person's family for a surrogate decision.[5] Many commentators agree that this practice is wrong and that surrogate decisions should not be substituted for a person's own decisions unless it is clear that the person is decisionally incapable (4,27,93,139,210,301, 417,671,901,945). On the other hand, some people who make judgments about dementia patients' decisionmaking capacity err in the opposite direction by assuming that a person with dementia is decisionally capable when he or she is not. Many commentators also agree that this practice is wrong because it fails to protect the decisionally incapable person from potentially harmful decisions (93,119,176,183,288,671).

Photo credit: Bill Adams

Some individuals with dementia are quite capable of making decisions about services for themselves, especially in the early stages of this disease. Surrogate decisions should not be substituted for an individual's own decisions unless it is clear that the individual is incapable of deciding for herself or himself.

Criteria for Determining Decisionmaking Capacity

Legal scholars and others have distinguished three general types of criteria for determining individuals' decisionmaking capacity:

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[5] Likewise, many of the State task forces and committees that have studied the problem of dementia begin with a statement that people with dementia gradually lose their decisionmaking capacity, but then jump immediately to a discussion of methods for surrogate decisionmaking, (99,531,713) leaving out any discussion of methods for determining individuals' decisionmaking capacity or supporting their ability to make decisions for themselves.

- status criteria,
- outcome criteria, and
- functional criteria (27,671).

If one uses status criteria to determine a person's decisionmaking capacity, the determination is based on the person's status in a specific category such as diagnosis, consciousness, or age. If one uses outcome criteria to determine a person's decisionmaking capacity, the determination usually is based on the "correctness" or "reasonableness" of the person's decision as judged by other people. If one uses functional criteria, the determination is based on some aspect of the individual's functioning or potential functioning in a decisionmaking situation (27,671).

Some of the physicians, case managers, and others who make judgments about the decisionmaking capacity of people with dementia are probably not even conscious of making the judgments, and it is very unlikely that many of them consider whether their judgments are based on status, outcome, or functional criteria. Anecdotal evidence suggests, however, that many of these individuals rely more on status and outcome criteria than on functional criteria.

Physicians, case managers, and others who automatically assume that any person with a diagnosis of a dementing disease is unable to make decisions are using *a status criterion*—a diagnosis of a dementing disease. As noted earlier, the use of this criterion to judge a person's decisionmaking capacity is not appropriate, because people with dementing diseases vary greatly in their cognitive abilities, and many of them retain sufficient cognitive abilities to make decisions for themselves, especially in the early stages of their disease.

Physicians, case managers, and others who use the "correctness" or "reasonableness" of an individual's decision to judge the individual's decisionmaking capacity are using *outcome criteria*. If a cognitively impaired person's decision conflicts with a recommendation or decision of the individual's physician, case manager, hospital discharge planner, or some other caregiver, the person's decision may be called "unreasonable" and automatically regarded as evidence that the person is decisionally incapable. If a cognitively impaired person's decision does not conflict with the recommendations or decisions of his or her caregivers, the issue of the person's decisionmaking capacity may not even arise (386,901,947).

Two different arguments are made about the appropriateness of using outcome criteria such as the "correctness" or "reasonableness" of a person's decision to judge the person's decisionmaking capacity. On the one hand, some argue, competent adults have a legal right to take risks and make foolish decisions so long as their decisions do not encroach on the rights of others or violate the law (41,93,181,539); people with cognitive impairments should not be deprived of that right. On the other hand, some argue, physicians and other health care and social service professionals have a legal and ethical obligation to protect vulnerable people from danger and neglect; if these professionals think that a cognitively impaired person's decision threatens the person's safety, they are obligated to question it (41,93,181). A middle ground that reconciles these two arguments, in theory at least, is the view that if a cognitively impaired person makes a decision that seems unreasonable to others, the decision should trigger a careful evaluation of the person's decisionmaking capacity but should not result in an automatic judgment that the person is decisionally incapable (945).

Physicians, case managers, and others who use some aspect or aspects of an individual's functioning in a decisionmaking situation to judge the individual's decisionmaking capacity are using *functional criteria*. Two commentators discussing discharge planning for elderly people with diminished decisionmaking capacity have defined functional decisionmaking capacity in terms of a person's ability to comprehend the possible consequences of a plan he or she proposes (181). Other commentators have identified four functional criteria for determining a person's decisionmaking capacity. Those criteria are listed below in the order of increasing strictness:

1. making a choice;
2. evidencing an understanding of relevant information and issues;
3. rationally manipulating the relevant information; and
4. in addition to 2 and 3 above, appreciating the nature of the situation (29).

The few courts that have considered criteria for determining decisionmaking capacity have generally adopted functional criteria rather than status or

Photo credit: Rush-Presbyterian/St. Luke's Medical Center, Chicago, IL

A person with dementia may be capable of making some decisions but not others.

outcome criteria (27). Most commentators also favor the use of functional criteria to determine a person's decisionmaking capacity, primarily because such criteria pertain directly to the person's actual or potential functioning in a decisionmaking situation (27). Functional criteria for determining a person's decisionmaking capacity are more ambiguous than status or outcome criteria, however. For that reason, a person who uses functional criteria has to exercise more independent judgment than a person who uses status or outcome criteria and may therefore need more training to make these determinations.

At least one observer has suggested that cognitive assessment tests, such as the Mini-Mental State Examination (218), could be used as an objective measure of decisionmaking capacity (613). That idea has intuitive appeal, but OTA is not aware of any research that compares people's cognitive ability as measured by their scores on a cognitive assessment test and their decisionmaking capacity as measured by some other standard, and anecdotal evidence suggests that such scores and decisionmaking capacity may not be highly correlated. Moreover, in some cases, people's scores on cognitive assessment tests are not even an accurate indicator of their cognitive abilities. Sometimes, the tests incorrectly identify people as cognitively impaired who are cognitively normal; this situation is particularly likely to occur when the tests are used for ethnic minority people and people with very little formal education (831,865).

Although commentaries on criteria for determining people's decisionmaking capacity favor the use of functional criteria over status or outcome criteria as a general principle, it is important to note that most of the discussion on this topic has occurred in the context of decisions about life-sustaining medical treatments and about participation in research.

Moreover, discussion has often focused on people other than those with dementia (e.g., mentally ill and terminally ill people). The implications of using functional rather than status or outcome criteria to determine dementia patients' capacity to make everyday decisions about health care, long-term care, social, and other services have received very little attention. Thus, it is unclear whether there are any special considerations in the use of functional criteria for this purpose and whether there may be certain functional criteria that are especially appropriate for this population.

The Concept of Decision-Specific Decisionmaking Capacity

A concept that has emerged in the legal and ethical debate about determining decisionmaking capacity is the concept of decision-specific capacity. That concept is that a person's capacity to make a decision may differ for each decision. A person may be capable of making a simple decision carrying little risk but not capable of making a more complex decision carrying significant risks (176,178,945). Furthermore, "a person may be [capable of making] a particular decision at a particular time, under certain circumstances, but [incapable of making] another decision, or even the same decision, under different conditions" (93).

The concept of decision-specific decisionmaking capacity is widely advocated and accepted (27,93, 177,671,672), but discussion about the application of the concept has occurred in the context of single decisions about the use of life-sustaining medical treatments or participation in research. So far, very little has been written about the application of this concept in the context of situations that call for making multiple interrelated decisions about a person's living arrangements and the use of various health care, long-term care, social, and other services over time.

Applying the concept of decision-specific capacity in situations involving multiple interrelated decisions over time may be considerably more difficult than applying the concept in situations where a single decision is needed. As an example, consider the dilemma raised in the following instance. A cognitively impaired man who requires supervision and personal care decides that he wants to remain at home with homemaker assistance instead of entering a nursing home. The man's physician, the case manager, and others agree that the man is capable of making that decision, and so the case manager arranges for homemaker services. Subsequently, however, the man refuses to pay or repeatedly fires the homemakers who are sent to help him. What should be done in a case like this—when a cognitively impaired person refuses to implement his or her own decision?

Several commentators have pointed out that some people who are capable of *making* a decision are not necessarily capable of *implementing* it (i.e., they have decisional autonomy but not executional autonomy), and that such people need assistance in implementing their decisions (139,179,384). The application of that principle is clear with respect to people who are *physically* unable to implement their decisions, but it is less clear in the case of a cognitively impaired person who refuses to implement his or her own decision. Does it make sense to conclude that such a person is decisionally capable with respect to one decision and decisionally incapable with respect to other decisions that are needed to implement that decision? Raising this dilemma is not intended to dispute the validity of the concept of decision-specific decisionmaking capacity. Rather, it is intended to illustrate the difficulty that a case manager or other arranger of services might encounter in seeking to apply the concept to decisions about services for people with dementia.

Who Should Determine Decisionmaking Capacity?

Many commentators believe that a person's decisionmaking capacity should be determined without court involvement whenever possible and that the courts should be called on as a last resort only if an irreconcilable disagreement about a person's decisionmaking capacity arises among those who are caring for the person (177,253,539,945). Such determinations are better made without court involvement, they say, in part because court proceedings tend to be expensive, time-consuming, and emotionally stressful for everyone involved. In addition, many months may pass before a court hears a case and issues a decision, and applying the concept of decision-specific decisionmaking capacity would be virtually impossible if many decisions about a person's care had to be made over time, and a court hearing had to be held to determine the person's capacity to make each decision.

If, as a general practice, determinations of people's decisionmaking capacity are to be made without court involvement, some person or body other than the courts has to make them. Some hospitals and nursing homes have established explicit institutional policies that delineate procedures to be followed in making decisions about the use of life-sustaining medical treatments, and their policies often include procedures for determining patients' decisionmaking capacity (475,833). In addition, some hospitals and nursing homes have an ethics committee—a multidisciplinary group established to address ethical dilemmas that arise within the facility and advise staff about difficult treatment decisions. Hospital and nursing home ethics committees sometimes assist facility staff in determining whether patients are capable of making decisions about their medical care (833).

Agencies that arrange services for people with dementia could establish explicit policies, not unlike the institutional policies just mentioned, that would delineate procedures to be followed when decisions about services are needed for clients of questionable decisionmaking capacity. The agency policies could specify procedures for determining such individuals' decisionmaking capacity, including instructions about who should be involved in making the determinations.

Some agencies that arrange services for people with dementia might be able to adapt the model of a hospital or nursing home ethics committee for determining their clients' decisionmaking capacity (179). OTA knows of one community mental health center in Spokane, Washington, that has established a multidisciplinary team consisting of a psychiatrist, a nurse, and a social worker to determine its clients' decisionmaking capacity (689).[6] Other agencies could use a similar approach.

In judging individuals' legal competency, courts frequently rely on the opinions of psychiatrists and psychologists. Some of the agencies OTA studied that arrange services for people with dementia—e.g., community mental health centers—have psychiatrists and psychologists as employees or consultants. These agencies might assign a psychiatrist or psychologist the primary responsibility for determining their clients' decisionmaking capacity.

Agencies that arrange services for people with dementia also might assign case managers the primary responsibility for determining their clients' decisionmaking capacity. OTA has heard different opinions about the wisdom of this approach, and some people's opinions depend on the educational background, experience, and training of the case managers who would be performing the function. Citing the important legal rights and legal and ethical issues involved in judgments about an individual's decisionmaking capacity, some people argue that only those case managers who have received special training in determining decisionmaking capacity—either in addition to or irrespective of their having a certain educational background and/or experience—are qualified to determine their clients' decisionmaking capacity. Other people argue that case managers with certain types of educational background and experience (e.g., those with a master's degree in nursing or social work and some amount of experience) are qualified to determine their clients' decisionmaking capacity. Still other people argue that case managers are not qualified to determine individuals' decisionmaking capacity regardless of the case managers' educational background, experience, and/or any special training they may have received.

It is important to note in this context that in many and perhaps most agencies that arrange services for people with dementia, case managers are the ones who determine their clients' decisionmaking capacity, even though there may be no explicit agency recognition that they are performing that function and some of the case managers may not aware that they are doing so. Some people might argue that the current situation is satisfactory, although OTA has not heard that opinion expressed (except with respect to case managers with certain educational background and/or experience).

The educational background and experience of individuals who function as case managers in agencies that arrange services for people with dementia varies greatly, but to OTA's knowledge, the question of how education and experience affect case managers' ability to determine people's decisionmaking capacity has not been systematically investigated. It is reasonable to believe, though, that whatever their background, case managers and others who arrange services for people with demen-

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[6] The Elderly Services Program of the Spokane Community Mental Health Center is described in box 8-C in ch. 8.

Photo credit: Eastern Area Agency on Aging, Brower, ME

In many agencies that arrange services for people with dementia case managers are the ones who determine their clients' decisionmaking capacity, even though there may be no explicit agency recognition that they are performing that function.

tia would benefit from training in determining decisionmaking capacity. The form such training should take and who should provide it are unclear, however.

A resource center established at the University of Minnesota in 1988 might be able to develop training materials about determining decisionmaking capacity for case managers and others who arrange services for people with dementia. This center, the Long-Term Care Decisions Resource Center, was established by the Federal Administration on Aging to conduct research and to provide State units on aging and area agencies on aging (AAAs) with training and technical assistance related to decisionmaking in long-term care. The Minnesota center is addressing a variety of topics related to long-term care decisionmaking, including client assessment, care planning, and other case management functions. In relation to its work on these topics, the center might be able to develop training materials about methods of determining decisionmaking capacity and about legal and ethical issues involved in judgments about an individual's decisionmaking capacity. Such materials could be used to train case managers in AAAs and then be disseminated to other agencies.

Methods of Enhancing Decisionmaking Capacity

Several commentators believe that physicians, other health care and social service professionals, hospital discharge planners, case managers, and others have an obligation to support and enhance the decisionmaking capacity of people with dementia (93,177,945). They also have an obligation to make the most of the variability in such individuals' decisionmaking capacity to allow individuals to make decisions for themselves to the greatest extent possible (93,177,945).

The decisionmaking capacity of a person with dementia is diminished first and foremost by cognitive deficits caused by the person's dementing disease. Since the cognitive abilities of a person with a dementing illness typically vary from day to day and even in the course of the same day, the person's decisionmaking capacity may be greater at some times than others. To allow the person to make his or her own decisions about services to the greatest extent possible, physicians and other health care and social service professionals must be available and willing to make the most of periods of relative lucidity (93,181).

In addition to being affected by the person's dementing disease, the decisionmaking capacity of a person with a dementing disease may be diminished by a variety of other factors that are more or less susceptible to interventions by physicians or others who are caring for the person. Such factors include medications, coexisting illnesses, stress, and unfamiliar environments that exacerbate the person's cognitive deficits, as well as sensory impairments that interfere with the person's ability to receive information relevant to decisions (93,414,945). Other factors include language barriers that interfere with communication; the lack of information about possible living arrangements and services, the form in which information about services is presented, and the ways in which questions about services and living arrangements are framed (4,179,386,798). Eliminating or compensating for factors that adversely affect decisionmaking capacity is one way to enhance a person's decisionmaking capacity and support the person's autonomy.

Unfortunately, the decisionmaking capacity of most individuals with dementia deteriorates over time. Another way to enhance the decisionmaking capacity and support the autonomy of such individuals, therefore, is by anticipating their mental deterioration and encouraging them to take advantage of legal arrangements that allow them to document their wishes or preferences with respect to certain types of decisions, so these wishes and preferences can inform future decisions by surrogate decisionmakers. Such legal arrangements include the following:

- trust agreements, which allow individuals to document their wishes for the management of their financial affairs in the event that they become decisionally incapable;
- living wills, which allow individuals to document their preferences about the use of life-sustaining medical treatments in the event that they become decisionally incapable; and
- durable powers of attorney, which allow individuals to designate someone to make health care and/or financial decisions for them (i.e., a surrogate decisionmaker) if the individual becomes decisionally incapable.

Many commentators have noted the importance of these legal arrangements and have emphasized that physicians, other health care and social service professionals, service providers, hospital discharge planners, case managers, and others who work with people with dementia and their families have a responsibility to encourage the patients and their families to have the necessary documents executed while the person is still decisionally capable (38,137,180,253,539,644,945).

If agencies that arrange services for people with dementia had explicit policies and procedures for determining their clients' decisionmaking capacity, they could incorporate available methods for enhancing decisionmaking capacity into their procedures. Implementing methods for enhancing decisionmaking capacity may be difficult, however, because the methods are often time-consuming; they do not fit easily into the time constraints of the typical hospital discharge planning process or situations in which services must be arranged quickly because the patient and family are in crisis by the time they come to the attention of the case manager (4,139,179,417,901).

The reason for enhancing individuals' decisionmaking capacity is to allow people to make decisions for themselves to the greatest extent that they are able. Efforts to preserve the autonomy of individuals with dementia have to be balanced, however, with a recognition that such individuals are often decisionally incapable and therefore may need protection from decisions that may be harmful to them (119, 183,288). Designating someone to make decisions about services for a person who is decisionally incapable is not depriving that person of autonomy. In fact, allowing such a person to make decisions for himself or herself may be more correctly construed as abandonment than as supporting autonomy (41,417,547).

A full discussion of the difficult legal and ethical considerations involved in supporting the autonomy of a person with questionable decisionmaking capacity v. protecting the person from potentially harmful decisions is beyond the scope of this report.[7] The main point here is that those seeking to support autonomy must balance their efforts with the recognition of realistic limits on autonomy caused by the person's dementing disease (41,178,546). Striking a balance between supporting a decisionally capable individual's autonomy and protecting a decisionally incapable person from potentially harmful decisions often requires subtle judgments on the part of whoever is determining the person's decisionmaking capacity—an observation that again suggests the need for training of the individuals who have to make these judgments.

Implications for an Effective System To Link People With Dementia to Services

As the preceding discussion points out, physicians, other health care and social service professionals, hospital discharge planners, case managers, and others who are involved in arranging services for people with dementia sometimes simply assume that anyone with a diagnosis of a dementing disease is decisionally incapable, without carefully evaluating the person's decisionmaking capacity. Furthermore, most agencies that arrange services for people with dementia do not have explicit policies and procedures for determining their clients' decisionmaking capacity. Judgments about clients' decisionmaking capacity in these agencies are frequently made by case managers and others who may or may not be knowledgeable about methods for determining decisionmaking capacity or about the complex legal and ethical issues involved in such judgments. (Some of these individuals may not even be aware that they are making the determinations.)

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[7] For further discussion of these issues and considerations as they relate to decisions about services for people with dementia, the reader is referred to the summer 1987 issue of *Generations*, "Coercive Placement of the Elderly: Protection or Choice?" and the June 1988 supplement to *The Gerontologist*, "Autonomy in Long-Term Care" (241,251).

If Congress mandated a national system to link people with dementia to services, Congress could require the agencies that were designated to constitute the system to have explicit policies and procedures for determining clients' decisionmaking capacity. The questions that would have to be addressed by agencies in establishing such policies and procedures include the following:

- What criteria should be used to determine decisionmaking capacity?
- Who should be involved in determining client's decisionmaking capacity?
- What procedures should be used to enhance clients' decisionmaking capacity while at the same time protecting decisionally incapable people from potentially harmful decisions?

None of these questions is easily answered. Some of the possible answers discussed in the preceding sections were developed in discussion and debate about determining decisionmaking capacity for other client populations and other types of decisions. More research and analysis is needed about procedures for determining decisionmaking capacity in people with dementia and in the context of decisions about the health care, long-term care, social, and other services that may be needed for them. Training about determining decisionmaking capacity could benefit case managers and others who arrange services for people with dementia. Such training is especially needed for case managers or other individuals who have primary responsibility for determining their clients' decisionmaking capacity.

MAKING SURROGATE DECISIONS ABOUT SERVICES FOR INDIVIDUALS WITH DEMENTIA

If an individual with dementia is decisionally incapable, decisions about services must be made for the individual. It is important to reemphasize, however, that making decisions for such a person is the *second* step. The process of making decisions about services should begin with a presumption that the individual is decisionally capable. Only after that presumption is refuted should other people make decisions for the person (946).

When decisions are made on behalf of an individual who is decisionally incapable, someone or some group of people is chosen as the surrogate decisionmaker, whether that choice is made explicitly or implicitly. Furthermore, the surrogate decisions are based on some criteria, whether those criteria are explicit or implicit. When decisions about services are made for an individual with dementia, the choice of a surrogate decisionmaker and the criteria for surrogate decisions are probably more often implicit than explicit. Nevertheless, who is chosen as the surrogate decisionmaker and what criteria are used for surrogate decisions can have a profound impact on the life of the individual with dementia.

Who Should Make Surrogate Decisions About Services?

As mentioned earlier, people who are decisionally capable can designate someone to make decisions on their behalf through the legal mechanism of a durable power of attorney. In some States, people who are decisionally capable also can designate someone to make decisions for them through another legal mechanism—a living will. Very few people have executed either a durable power of attorney or a living will. Moreover, the types of decisions that can be made with a durable power of attorney vary from State to State, and it is often unclear whether or to what extent a durable power of attorney authorizes the designated surrogate to make decisions about the kinds of health care, long-term care, social, and other services that may be needed for a person with dementia. State living will laws that allow the designation of a surrogate decisionmaker generally only authorize surrogate decisions about the use of life-sustaining medical treatments and, in some States, only for terminally ill individuals.

If a decision about services is needed for a decisionally incapable person with dementia and the person has not formally designated a surrogate decisionmaker, physicians, other health care and social service professionals, service providers, hospital discharge planners, case managers, and others usually turn to the person's family (if the person has one). Available evidence, including a 1982 Harris poll and a more recent study, indicates that most people want a family member to make decisions for them if they are not able to make the decisions themselves. The 1982 Harris poll found that 57 percent of the 1,251 people interviewed nationwide said they wanted a family member to make important medical decisions for them if they were not capable of doing so themselves; about one-third wanted their doctor to make such decisions (476). In another, more recent study, 90 percent of the 40 elderly persons interviewed said they wanted a family member or family members to make health care decisions for them if they were not capable of doing so themselves; the remaining 10 percent wanted their doctor, a lawyer, or a close friend to make the decisions (322).

The 1982 Harris poll and the more recent study both focused on health care decisions, and although the majority of respondents in both studies said they wanted family members to make surrogate decisions for them, the next largest number of respondents said they wanted their physician to make the decisions (322,476). Physicians are probably perceived by most people as more qualified to make decisions about health care than about some of the other kinds of services that may be needed for individuals with dementia. No data are available, but it is likely that if the studies had focused on decisions about social and other nonmedical services, the preference for family members as surrogate decisionmakers would have been even stronger.

Despite the fact that most people prefer to have family members make decisions for them if they become decisionally incapable, many States provide no legal authority for family members to make the decisions unless the family member is designated as a surrogate decisionmaker by a durable power of attorney or a living will, as just described (36,531,945).

As of April 1987, only 15 States had "family consent laws" (i.e., statutes that authorize family members to make decisions for relatives who are decisionally incapable), although courts in 5 additional States had ruled that family members could make such decisions (539,540). These family consent laws and court rulings generally only apply to certain types of patients and certain types of decisions. The laws and court rulings in some States authorize families to make decisions for a decisionally incapable relative only if a physician has certified that the person is terminally ill (540). Many existing family consent laws and court rulings only address decisions about life-sustaining medical treatments, and it is not clear whether they apply to decisions about the other kinds of health care, long-term care, social, and other services that may be needed for people with dementia.

In States that do not have family consent laws, the legal rights and responsibilities of family members and others in making decisions for decisionally incapable people are unclear. In these States and in many of the States that already have family consent laws, legislation is needed to clearly delineate the extent of, and limitations on, the decisionmaking authority that is granted to family members and others, including any limitations on the types of decisions that the law authorizes them to make. The designation of surrogate decisionmakers, including family members, for decisionally incapable people with dementia will continue even in the absence of such legislation, but State statutes that clearly define the rights and responsibilities of family members and others in making decisions for decisionally incapable people and also delineate the types of decisions that a designated surrogate is and is not authorized to make would create a firm legal basis for determining who should make decisions about services for decisionally incapable people with dementia.

Photo credit: Maria P. Cordero-Aranda

Most people want family members to make decisions for them if they are not capable of making the decisions themselves.

Several problems complicate the practice of using family members as surrogate decisionmakers. One is that a person's relatives may disagree about which one(s) should make the necessary decisions. Such disagreements may arise between the demented person's adult children, between adult children and the spouse, or between siblings and other relatives who have been involved in caring for the person (85,137,186,514,670,936). Some States' family consent laws address this problem by specifying the order in which certain family members (e.g., the spouse and the adult children) are authorized to make surrogate decisions (539). OTA has not analyzed the pros and cons of this approach.

Some of the other problems that complicate the practice of using family members as surrogate decisionmakers probably would persist even if all States had clear, comprehensive statutes on designating surrogate decisionmakers. One such problem, as discussed in chapter 3, is that some family members are not comfortable making decisions for a relative with dementia (307,487,533,669,936). Despite their concern about their relative's welfare and knowledge about his or her wishes, some family members are reluctant to take control. Such reluctance is evident in following statement of a 74-year-old woman whose husband had dementia:

> My husband refuses to believe that there is anything wrong with him. Sometimes he does seem to be better than others, so how do I tell him that he needs help? (669)

A study of 15 spouses of people with dementia found that wives were much more likely than husbands to have difficulty making decisions for their demented spouses (533). The researcher concluded:

> The males' assumption of authority over their wives was . . . a natural extension of their authoritative role in the family. For the wives, assuming an authority position over another adult, especially a man who had probably been the authority figure in the marriage, was one of the hardest aspects of the caregiving role (533).

Another problem that complicates the practice of using family members as surrogate decisionmakers is that some families are not appropriate surrogate decisionmakers. The practice of turning to a person's family for surrogate decisions assumes that family members are more likely than other people to know the patient's values and preferences and to be concerned about his or her interests. That assumption is valid in many cases, and perhaps most, but certainly not in all (93,945). Furthermore, even family members who know a patient's values and preferences and are concerned about the patient's interests, do not always make decisions on the basis of those values, preferences, and interests.

It is sometimes assumed that the only thing a case manager has to do with respect to designating a surrogate decisionmaker for a person with dementia who has a family is to note the name and telephone number of one or more family members in the person's medical record or care plan. Sometimes, however, problems arise—e.g., the person's relatives disagree about who should be the surrogate decisionmaker, or the obvious surrogate is either reluctant to make decisions for the person or unconcerned about the person's well-being—that make designating a surrogate a more difficult task. Such problems suggest a need for agency policies and procedures for designating surrogate decisionmakers (written to comply with existing State laws if there are relevant laws) and training for case managers and others who are involved in selecting surrogate decisionmakers.

Designating a surrogate decisionmaker for a person with dementia who has no family is likely to be even more difficult than doing so for a person who has a family. One unresolved issue is the appropriate role of nonfamily caregivers in making decisions about services for decisionally incapable people with dementia. That issue was brought to OTA's attention by the findings of an exploratory study conducted for OTA in Los Angeles and San Diego Counties, California in 1988 and 1989 (866). One component of the study was interviews with 88 ethnic minority caregivers of ethnic minority people with dementia. The 88 caregivers included 35 black, 25 Hispanic, 18 Japanese, and 10 American Indian caregivers.[8] The study found that 17 percent of the caregivers were friends or neighbors of the person they were caring for, i.e., not family members, and 34 percent of the black caregivers were not family members.

OTA's contractors, the individuals who interviewed the black caregivers, and others have pointed out that in many black communities, long-time friends and neighbors are frequently regarded and spoken about as if they were family members (247,866). When it comes to making decisions about services for a decisionally incapable person, however, these ''fictive kin'' are in the same or perhaps an even more uncertain position legally than family caregivers in States that do not have family consent laws. Although a nonfamily caregiver may know more than anyone else about the wishes and values of the person he or she is caring for—and therefore be the best surrogate decisionmaker for that person—there is no legal authority for the nonfamily caregiver to make the necessary decisions.

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[8] All of the components of the study conducted for OTA in California are described in app. A. A complete report on the study is available from the National Technical Information Service in Springfield, VA.

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The study conducted for OTA in Los Angeles and San Diego Counties found that the percentage of nonfamily caregivers was higher among the black caregivers than among the Hispanic, Japanese, and American Indian caregivers (866). These findings cannot be generalized with any certainty because of the small size of the samples and the way the samples were recruited. OTA's contractors believe, however, that there is probably a higher percentage of nonfamily caregivers of people with dementia in the black population than in the Hispanic, Japanese, or American Indian populations in the areas studied (865). On the other hand, anecdotal evidence suggests and OTA's contractors believe that the phenomenon of nonfamily caregivers of people with dementia exists in all population groups, including the majority white population. It is likely, therefore, that agencies, case managers, and others that arrange services for people with dementia routinely encounter dementia patients who have nonfamily caregivers. Although the appropriate role of these caregivers in decisions about services for the patients is unclear, it is clear that unless the caregivers are involved in the decisionmaking process in some way, decisions about services for the patients they are caring for will be made without the benefit of their knowledge of the patients' wishes and values.

For individuals with dementia who have no family member or other person to make decisions about services for them and for individuals whose family or nonfamily caregiver is not an appropriate surrogate for any reason, one option would seem to be guardianship—in which a court appoints someone to manage money and make decisions for an individual who has been declared legally incompetent (the ward).[9] Many commentators regard guardianship as a last resort, however, because it usually entails the drastic deprivation of rights for the ward; because, as discussed earlier, court proceedings are often expensive, time-consuming, and emotionally stressful for everyone involved (177,253,361,945); and because guardianship does not necessarily result in the designation of a reliable surrogate decisionmaker.

A full discussion of the many problems with guardianship in this country is beyond the scope of this report. It is sufficient to note some of the findings of a study conducted by the Associated Press in all 50 States in 1986 and 1987, in which judges, guardians, and others were interviewed and the court files of more than 2,200 individuals who had been declared legally incompetent and assigned a guardian were reviewed (11). That study found that in one-fourth of the cases, no hearing was held to determine whether the person was incompetent. In many cases, once guardianship was established, the court lost track of the paperwork, the guardian, and the ward. Although there are reporting and accounting requirements for court-appointed guardians in all 50 States, the required annual or periodic accountings of the ward's money were missing or incomplete in half the files. Only 16 percent of the files had any kind of report on the status of the ward, and 13 percent of the files were empty except for the original decision that the individual was incompetent and the granting of guardianship powers. One judge interviewed by the Associated Press said:

> I don't know where the wards are, who's caring for them, or what they're doing. I have no support staff; I have no welfare workers; I have no aides; I have no assistants; and I have no money (11).

In 1983, Montefiore Hospital in New York added a lawyer to its multidisciplinary geriatric team to resolve legal problems that prevented effective hospital discharge planning for or appropriate placement of elderly patients with diminished cognitive abilities (181). For some patients, the lawyer initiated legal proceedings in order to have a guardian appointed to manage the patient's money so that needed services could be purchased. After several protracted and generally unsatisfactory experiences with the guardianship process, the lawyer concluded that guardianship was an inadequate method of designating a surrogate decisionmaker for the purpose of hospital discharge planning (179). Another lawyer connected to the project described the guardianship process as "a nonexistent alternative" with respect to hospital discharge planning (946). The guardians appointed by the court generally were untrained and unsupervised. Moreover, in at least two cases in which a guardian was appointed after a lengthy court process, the person appointed did not even contact the patient or patient's caregivers for months after the court decision (181).

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[9] Some States use the terms "guardian" and "guardianship," other States use the terms "conservator" and "conservatorship," and some States use both terms to refer to the court-appointed person and the mechanism(s) by which that person is appointed to manage the assets and/or make other decisions on behalf of people who are determined to be decisionally incapable (539). In the following discussion, the terms "guardian" and "guardianship" are intended to include both sets of terms.

The American Bar Association has recommended reforms in the guardianship process, and the Center for Social Gerontology in Ann Arbor, Michigan, has developed standards for individuals and agencies that function as guardians for decisionally incapable adults (738). Various other organizations have developed alternatives to guardianship for decisionally incapable people who have no family member or other surrogate decisionmaker.

The University of New Mexico's Institute of Public Law, for example, recently trained 20 volunteers (social workers, lawyers, nurses, and others) to act as "temporary treatment guardians" to make decisions about medical treatment for hospitalized elderly people who are decisionally incapable and have no other surrogate decisionmaker (802). The volunteers underwent a 16-hour training program that involved didactic presentations, case discussions, and role playing. In the course of the 1-year project, the volunteers assisted a total of 50 elderly people. As it turned out, the temporary treatment guardians discovered that some of the elderly people they were called in to assist were decisionally capable after all and that other clients had family members or close friends who could be located with a little "sleuthing" and were able to make decisions for the person.

Since 1985, New York State has had a program whereby volunteer surrogate decisionmaking committees make decisions about medical treatments for mentally ill and mentally retarded people who have no other surrogate decisionmaker (777). The committees are composed of at least 12 members who meet in 4-member panels to consider treatment decisions. Each 4-member panel must include a health care professional, a former patient or relative of a patient, a lawyer, and an advocate for the mentally disabled. For each mentally ill or retarded individual, the 4-member panel determines, first, whether the person is decisionally capable and, second, whether there is a family member or a legally appointed guardian who can make the necessary treatment decision. If the answers to both questions are no, the panel makes the treatment decision. In the first year of the program, surrogate decisions about treatment were made in 192 cases. The decisions were made in an average of 14 days from the time the committees received the application—much less time than is required for the typical guardianship proceeding. Some observers feared that it would be difficult to recruit professionals to serve on the committees, but recruiting volunteers has not been a problem except in some rural areas of the State.

Both the University of New Mexico program and the New York State program provide only a one-time or temporary surrogate decisionmaker and address only decisions about medical treatment. Other guardianship diversion programs provide money management and counseling services for decisionally incapable people, sometimes on a long-term basis (900). All of these programs exemplify methods other than guardianship by which surrogate decisionmakers can be provided for people who are decisionally incapable and have no family member or other surrogate to made decisions for them. To make surrogate decisions for these people, agencies that arrange services for people with dementia could create their own surrogate decisionmaking committee, recruit and train volunteer surrogate decisionmakers, or affiliate themselves with a program that provides surrogate decisionmakers (if such a program is available in the agency's area).

What Criteria Should Guide Surrogate Decisions About Services?

Court rulings and legal analysis of decisions about the use of life-sustaining medical treatments made on behalf of people who are decisionally incapable have identified two standards to guide surrogate decisionmaking:

- the best interest standard, and
- the substituted judgment standard.

The best interest standard requires the surrogate to make decisions from the perspective of a hypothetical reasonable person, using objective, societally shared criteria (945). The substituted judgment standard requires the surrogate to make decisions from the perspective of the patient, using the patient's personal values and preferences (945).

The best interest and substituted judgment standards, respectively, represent two fundamental values in surrogate decisionmaking—patient autonomy and patient well-being (671). The tension between those two values is as central to surrogate decisions about services for people with dementia as it is to surrogate decisions about the use of life-sustaining medical treatments for people who are permanently unconscious or terminally ill. In the context of surrogate decisions about services for people with dementia, patient well-being as a value is manifested in decisions by physicians, service providers, case managers, or an individual's friends or family that the individual should receive certain services or live in a certain place "for his or her own good," regardless of the individual's wishes. Patient autonomy as a value is manifested in surrogate decisions that an individual with dementia should be allowed to refuse services and live as he or she chooses, even if there is risk associated with those choices. The latter perspective also is reflected in efforts to enhance an individual's decisionmaking capacity, as discussed earlier, and to support the "residual autonomy" of the individual (177).

Some people generally favor surrogate decisions based on patient well-being, whereas others generally favor surrogate decisions based on patient autonomy. Clearly, however, neither value by itself is sufficient for every decision or for every patient. The process of making surrogate decisions about services for people with dementia probably should retain a tension between the two values, but retaining that tension means that in many cases the "right" decision will not be obvious.

When case managers, hospital discharge planners, and others who arrange services for people with dementia make or influence decisions about services, those decisions are likely to reflect their preference for one value or the other, either in general or in the particular situation. Yet some of those individuals may not be aware of the values involved in such decisions or the implications for the patient of decisions that favor one value over the other.

The relationship between patient well-being and autonomy has been discussed and debated extensively with respect to decisions for all kinds of people who are decisionally incapable, and the resulting ideas and principles seem both relevant to and adequate for thinking about criteria for surrogate decisions pertaining to the use of services for people with dementia. In contrast, another issue—how the needs, preferences, and best interests of the patient and of the family should be weighed—has received less attention in discussion and debate about decisions for all kinds of people who are decisionally incapable, and the resulting ideas and principles are less helpful in thinking about decisions about services for people with dementia.

Photo credit: Bill Adams

Agencies that arrange services for people with dementia could create a surrogate decisionmaking committee to make decisions about services for people with dementia who are not capable of making the decisions themselves and have no one else to make the decisions for them.

The members of the advisory panel for this OTA study talked at some length about the question of the relative weight that should be given to the needs, preferences, and best interests of the family v. the patient in decisions about services for persons with dementia. No consensus was reached, but several important points emerged from the discussion. First, it is clear that when family members are necessary participants in a plan of care because the person with dementia lives with them or for any other reason, their needs and preferences must be considered in decisions about services because their interests are at stake in the decisions and because they may not cooperate with the plan of care otherwise. Second, it is sometimes very difficult in practice to separate the needs, preferences, and best interests of the person with dementia and of the family.

Beyond those two points, the OTA advisory panel divided into two groups. Some panelists tended to regard the person with dementia and family as a unit and to consider that unit the appropriate client of the case manager. Those panelists generally were not especially concerned about the difficulty of separating the needs, preferences, and best interests of the patient and those of the family; and they seemed to regard positively the idea of using the needs, preferences, and best interests of the family as criteria for decisions about services. Other panelists tended to regard the person with dementia and family as separate; and they were worried about the potential for conflicts of interest if the needs, preferences, and best interests of the family, rather than those of the patient, were used as criteria for decisions about services.

Both groups of OTA advisory panel members were critical of case managers who represent themselves as advocates for a person with dementia but in fact have their primary allegiance to a relative of the person, a trust officer, or someone else who is paying for their services. This is one of the situations that commentators refer to with the phrase, "Who's the client?" The allegiance of the case manager to the impaired person v. a family member, trust officer, or someone else is in part a question of professional ethics that should be addressed in case management standards and is addressed, to some degree, in the case management standards of the National Association of Social Workers (572) and the National Council on the Aging (581).

A more complex issue is the relationship between the long-term needs, preferences, and best interests of a person with dementia and the needs, preferences, and best interests of his or her primary caregiver, who is usually a family member. Arguably, the long-term best interests of many people with dementia is to remain with a family caregiver even if the care they receive from that person is much less than ideal. It may be in the demented person's best interest to remain with the family caregiver because the alternative to being cared for by the family caregiver is objectively worse, is worse in the view of the patient, or both; because the person knows the family caregiver; or because families often provide what one commentator has called "substituted memory of shared happenings"—i.e., a knowledge of the patient's past (which a formal service provider generally does not have) that is reassuring to the patient and may to some degree compensate for his or her memory loss (177).

On the other hand, there is clearly some point at which the long-term best interests of a patient with dementia are not served by remaining with the family caregiver. Different observers undoubtedly would disagree about when that point has been reached for an individual patient.

If by basing decisions about services on the needs and preferences of the caregiver, one can support the caregiver and prolong the time he or she is willing and able to continue caring for the patient, doing so would seem to be in the patient's long-term best interest, even if it required disregarding the patient's "spoken choice" or short-term best interest. "Spoken choice" here refers to a clearly articulated preference of the person which, because of the person's cognitive impairment, may or may not reflect his or her real needs, preferences, or best interests (181).

Consider, for example, a situation in which a person with dementia is placed in a nursing home for 2 weeks against his or her wishes, so that the primary caregiver will be temporarily relieved of caregiving tasks. Even if the placement results in short-term worsening of the impaired person's cognitive and emotional status, some people would say that it is in that person's best interest because it serves the person's presumed long-term interests. Additional situations also might be imagined in which disregarding the spoken choice and short-term best interest of a decisionally incapable person could be regarded as being in that person's best interest.

The point of this discussion is not to resolve the question of the relative weight that should be given to the needs, preferences, and best interests of the person with dementia v. the family in decisions about services but simply to emphasize the complexity of the issue. Three additional considerations further complicate the matter. First, some people with dementia live with and are cared for by a person who is almost as impaired as they are and who might be legitimately regarded as a client. When there are, in effect, two clients in the home, how should their needs, preferences, and best interests be weighed in decisions about services? Second, some, and perhaps many caregivers can be pressured into doing more than they should do for their own good. Are there limits that could or should be applied to what a caregiver is expected, asked, or even allowed to do? Lastly, as a patient's condition deteriorates, is there a point at which the interests and well-being of the caregiver should take precedence over the interests of the patient?

There are no simple answers to any of these questions. Case managers and others who arrange services for people with dementia regularly confront situations in which decisions must be made that could favor the needs, preferences, and best interests of the family over those of the patient, or vice versa. They may be more or less aware of the issues involved in those decisions and the implications for the patient and family of decisions that favor the needs, preferences, or best interests of one over the other.

The question of the relative weight that should be given to patients' v. families' needs, preferences, and best interests in decisions about services requires further analysis. In the meantime, it is unclear what guidelines might be given to case managers and others who arrange services for people with dementia and thus regularly confront situations in which a decision must be made. One approach would be to create within agencies various forums (e.g., multidisciplinary team meetings, formal case conferences, and supervisory conferences) in which those situations could be discussed and deliberated.

Implications for a System To Link People With Dementia to Services

The preceding discussion points out that choosing surrogate decisionmakers for decisionally incapable people with dementia and determining what criteria should guide surrogate decisions about services for them involve complex legal and ethical issues and raise many unanswered questions. State legislation that clearly defined the rights and responsibilities of family members and others in making decisions for decisionally incapable people and delineated the types of decisions that designated surrogates are and are not authorized to make would eliminate many of the existing problems in designating surrogate decisionmakers. Even without such legislation, however, agencies, case managers, and others that arrange services for people with dementia have to turn to someone for surrogate decisions for decisionally incapable clients. Furthermore, it is likely that regardless of the specificity of State legislation, the designation of appropriate surrogate decisionmakers for people with dementia will entail difficult judgments in some and perhaps many cases because of the idiosyncrasies of each patient's situation.

Likewise, although it is generally agreed that patient autonomy and patient well-being are the values that should guide surrogate decisions, the two values often imply different decisions in the same situation, and neither value is appropriate for every situation. Applying the two values in decisions about the use of services for an individual client therefore entails difficult judgments in many cases. Balancing the needs, preferences, and interests of an individual with dementia and the needs, preferences, and interests of the individual's family also requires difficult judgments.

The need for these difficult judgments suggests that agencies that arrange services for people with dementia should have explicit policies and procedures for designating surrogate decisionmakers and making decisions about services for people with dementia who have no surrogate decisionmaker. It is reasonable to believe that case managers and others who are involved in arranging services for people with dementia would benefit from training about the issues involved in surrogate decisionmaking. To the extent that case managers and others who arrange services for people with dementia actually designate surrogate decisionmakers and/or make decisions about services for their decisionally incapable clients, their need for such training is increased.

If Congress mandated a national system to link people with dementia to services, Congress could require the agencies that were designated to constitute the system to have explicit policies and procedures for designating surrogate decisionmakers (written to comply with existing State laws if there are relevant laws) and for making surrogate decisions in instances where the agency had to make surrogate decisions for any reason. To formulate such policies and procedures, the agencies that constitute the linking system would have to address many of the unresolved questions discussed in this chapter, including questions about what to do when a decisionally incapable client's relatives disagree about which one of them should make the necessary decisions, how nonfamily caregivers should be involved in decisions about services, and when formal guardianship is needed for a client.

To support agencies' efforts to develop policies and procedures for designating surrogate decisionmakers and for making decisions for decisionally incapable clients who have no surrogate, more research and analysis pertaining to many of the questions discussed in the preceding sections is needed. Especially problematic is the question of how to balance the needs, preferences, and interests of an individual with dementia and the needs, preferences, and interests of the individual's family or other informal caregiver. Perhaps it would be useful for government, private agencies that arrange services for people with dementia, and professional associations that represent social workers, nurses, and other professionals who function as case managers to jointly sponsor forums for further discussion of this and related issues.

CONCLUSION

Questions about how to determine the decisionmaking capacity of people with dementia and how to make surrogate decisions about services for people who lack the capacity to make such decisions themselves are inherent in the process of arranging services for people with dementia. The way such questions are answered involves fundamental legal rights of the patient and raises complex legal and ethical issues. Those rights and issues are at stake regardless of whether the individuals who make or participate in the decisions are aware of them.

In many agencies that arrange services for people with dementia, questions about the methods used to evaluate clients' decisionmaking capacity and to make surrogate decisions about services for clients who cannot make such decisions themselves are obscured by other problems and concerns and by the severe constraints on the time within which decisions about services must be made. In such agencies, concerns about clients' legal rights, and about the legal and ethical issues involved in the way decisions about services are made for people with diminished decisionmaking capacity seem to be second-level concerns to be considered when other problems have been solved.

This chapter has suggested that if Congress mandated a national system to link people with dementia to services, Congress could require that any agency that is part of the system have explicit policies that delineate the procedures to be followed when decisions about services are needed for clients with diminished decisionmaking capacity. Policies that specify procedures for determining a client's decisionmaking capacity and/or assign responsibility for determining a client's decisionmaking capacity to a person or group of people could help increase the likelihood that clients' rights and the legal and ethical issues involved in decisionmaking are adequately considered.

The chapter has discussed some concepts, distinctions, and approaches that may be useful in developing such agency policies and procedures and in training case managers and others who are involved in arranging services for people with dementia. As noted repeatedly, many of the concepts, distinctions, and approaches that have been discussed were derived from analysis and debate about the use of life-sustaining medical treatments or participation in research, not the kinds of decisions that are the topic of this OTA report. Furthermore, some of the concepts, distinctions, and approaches discussed in the chapter apply more to decisionmaking by and for mentally ill and terminally ill people than to decisionmaking by and for people with dementia. To address the difficult questions and issues that are likely to arise in situations involving decisions about the many kinds of services to which an effective linking system could link people with dementia, further research, discussion, analysis, and debate is needed.

Chapter 5

Concerns About the Quality and Appropriateness of Services

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Chapter 5

Concerns About the Quality and Appropriateness of Services

INTRODUCTION

The quality of all kinds of health care, long-term care, social, and other services that may be needed for people with dementia varies greatly from one agency and individual service provider to another.[1] Numerous reports document the poor quality of care provided by some nursing homes (563,759,813,835), board and care facilities (66,166,775,816), and to a lesser extent home care agencies (821,305,852). At the same time, these reports indicate that other nursing homes, board and care facilities, and home care agencies provide excellent care. Differences in quality are typical not only of these types of services, but of all kinds of services that may be needed for people with dementia.

In addition to differences in quality, there are differences in services provided by various agencies and individuals that make the services more or less consistent with the needs of people with dementia. In communities that have more than one nursing home, home care agency, adult day center, physician, lawyer, or any other type of agency or individual service provider, the services offered by one agency or individual may be much more appropriate for people with dementia than the services offered by another agency or individual.

All people who need health care, long-term care, social, or other services are at risk of poor quality or inappropriate care, but people with dementia are particularly vulnerable. Because of their cognitive deficits, they may be unable to identify or articulate their care needs, to evaluate the services they receive, to remember and report instances of poor care, or to be believed. Realizing that people with dementia are so vulnerable, families and other informal caregivers are often extremely concerned about the quality and appropriateness of services they may use for these people.

This chapter focuses on the potential role a federally mandated linking system might play with respect to the quality and appropriateness of services to which it connects people with dementia. The *quality* of a service is defined here as the extent to which the service increases the probability of desired outcomes and reduces the probability of undesired outcomes, given the constraints of existing knowledge.[2] The *appropriateness* of a service denotes the aspects of a service that make it consistent with the needs of people with dementia.

In theory, a federally mandated linking system could take any of several different approaches with respect to the quality and appropriateness of services to which it connects people with dementia.

- The linking system could not concern itself with the quality and appropriateness of the services; it could provide no information about the quality and appropriateness of services and rely on families and others who are concerned about quality and appropriateness to obtain for themselves any information they need to evaluate the services.
- The linking system could refer families and others to specific sources of information about the quality and appropriateness of services.
- The linking system could provide families and others with information about the quality and appropriateness of the services.
- The linking system could refer people to or arrange for them only services that met specified standards of quality and appropriateness. (In the case of a linking system that also pays for services, this alternative would mean that the system would only pay for services that met the specified standards.)
- If the linking system provides services, it could assure the quality and appropriateness of those services directly.

In practice, three problems would make it difficult to implement these approaches or would limit their potential effectiveness. First, several of the approaches assume that there are accepted criteria for evaluating the quality and appropriateness of services for people with dementia. In fact, as discussed in this chapter, there is currently no consensus about criteria for evaluating the quality and appropriateness of services for people with dementia.

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[1] See table 1-2 in chapter 1 for a list of services that may be needed for people with dementia.

[2] This definition of quality was also used by OTA in its 1988 assessment, *The Quality of Medical Care: Information for Consumers* (832).

Second, several of the approaches assume that accurate information about the quality and appropriateness of services for people with dementia is available from various sources. Although one hears many recommendations about possible sources of such information, the analysis in this chapter indicates that accurate information about quality and appropriateness is not consistently available from any of the recommended sources.

Third, several of the approaches assume that families and other informal caregivers are able to gather information about the quality and appropriateness of services from one or more sources or to use lists of questions and criteria to evaluate services themselves—in short, that families and others are able to function as "informed consumers" in evaluating the quality and appropriateness of services. Although some families and other informal caregivers of people with dementia are certainly able to function as "informed consumers" in this context, others are not for a variety of reasons described in the chapter.

Probably the most important step that could be taken to enable a federally mandated linking system to connect people with dementia to the best available services would be the development of criteria to evaluate services. Certainly, if a federally mandated linking system were going to refer people to or arrange for them only services that met certain standards, the standards would have to be based on accepted criteria. If such criteria were available, some families could use the criteria to evaluate services themselves. Other agencies and organizations could also use the criteria to evaluate services, thus making accurate information about the quality and appropriateness of services available from these sources. The development of criteria for evaluating the quality and appropriateness of services for people with dementia is not the function of a linking system, but ways in which the necessary criteria might be developed and some criteria that might be considered are discussed later in this chapter.

The chapter focuses primarily on *quality assessment* (i.e., the measurement and evaluation of quality) rather than on *quality assurance* (i.e., procedures and activities to safeguard and improve quality by assessing quality and taking action to correct any problems found). The focus on quality assessment reflects the perspective of families and others who are trying to identify good services for a person with dementia, but who usually are not involved in assuring the quality and appropriateness of services.

Some agencies that link people to services also provide services and therefore can assure (i.e., assess and correct problems in) the quality of those services directly. Other agencies that link people to services contract for some of the services, and some of those agencies have procedures for monitoring and controlling the quality of contracted services. The last section of this chapter describes some of those agencies' procedures for monitoring and controlling quality, including procedures that involve patients and families in monitoring and controlling the quality of the services they receive.

Quality of care and methods of assessing and assuring quality are currently a concern of Congress and the topic of many publicly and privately funded research projects. Interest in quality of care has increased because of widespread concern that cost-containment measures introduced in the past few years may be reducing quality of care (111,831,925). Attention has focused primarily on the quality of hospital and nursing home care, but the focus is expanding now to include in-home and other noninstitutional services (206,216,471,658). In considering the potential role of a federally mandated linking system with respect to the quality and appropriateness of services to which it links people with dementia, this chapter is discussing all types of services that may be needed for these people.

FAMILY CAREGIVERS' CONCERNS

Numerous studies and anecdotal reports emphasize the strong commitment of many family caregivers to their relative with dementia. With this commitment comes a deep concern about the quality and appropriateness of any services provided for the person. According to one Office of Technology Assessment (OTA) contractor who studied 500 family caregivers of people with dementia:

> What was most impressive from (the) caregiver studies was the emotional investment that caregivers have in their responsibilities. This emotional tone may be reflected in rage at unsympathetic agencies or professionals, fear, grief, advocacy, resignation, humor, but most of all love for and commitment to an impaired older person. With such a strong personal investment, these family caregivers were predictably critical consumers of services and programs in their behalf (291).

A 1986 survey of family caregivers conducted for OTA found that family caregivers were indeed "critical consumers" who were concerned about the quality and appropriateness of services available to their relatives and other people with dementia (926). Other studies report similar findings (145,412). Many of the State task forces and committees that have studied the problem of Alzheimer's disease and related disorders also note families' grave concerns about the quality and appropriateness of services (99,143,246,360,396,408,531,541,598,621,870,920).

Some family caregivers are fearful about using services for a person with dementia because they believe that the quality of care provided will be poor and that the service providers will not know how to take care of a person with dementia (88,145,291, 396,599). Some family caregivers feel—often realistically—that no one will take as good care of their demented relative as they do. Some fear that their demented relative's inability to express needs or report inadequate care will cause service providers to neglect the person. Others fear that their demented relative's troublesome behavior or psychiatric symptoms will cause that person to be physically or verbally abused. Some families are apprehensive about using in-home services for a relative with dementia because they are afraid that the workers will be poorly trained and unreliable. Families who have had problems with one service provider may be afraid to try another one.

Some health care and social service professionals, case managers, government planners, policy analysts, and others seem to regard concerns about the quality of services as secondary to the problem of insufficient availability of services. A number of the people whom OTA asked about evaluating the quality and appropriateness of services for people with dementia responded that there is often no choice about services. In many localities, they said, families are lucky if there are *any* services available—let alone services that are appropriate for a person with dementia and of high quality.

The concern about insufficient availability of services is legitimate. The important point to be made here, however, is that even when services are available, there are some situations in which families' concerns about the quality and appropriateness of the services are the determining factor in their decisions about whether or not to use the services. Some families may choose not to use an available service because they believe that the service is inappropriate for the patient or of poor quality. Likewise, some families who have been reluctant to accept help may decide to use a service if they believe it is appropriate for the patient and of good quality.

OTA does not know how often either of the situations just mentioned occur or whether the frequency of their occurrence varies for different types of services. That there are situations, however, in which considerations of quality and appropriateness are the determining factor in families' decisions about service use suggests that although some health care and social service professionals, case managers, government planners, policy analysts, and others may regard concerns about the quality and appropriateness of services as secondary to the problem of insufficient availability of services, the families of people with dementia may not always agree. In the view of at least some families in some situations, services that are available but of poor quality or inappropriate for the patient may just as well not exist.[3]

CONCEPTUAL AND PRACTICAL DIFFICULTIES IN EVALUATING SERVICES

Many people think they know quality when they see it, but they have difficulty defining its components precisely. This predicament is described in a frequently cited passage from *Zen and the Art of Motorcycle Maintenance:*

> Quality you know what it is, yet you don't know what it is. But that's self-contradictory. But some things *are* better than others, that is, they have more quality. But when you try to say what quality is apart from the things that have it, it all goes *poof*! There's nothing to talk about. But if you can't say what Quality is, how do you know what it is, or how do you know it even exists? (663).

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[3] Clearly, considerations of quality and appropriateness do not *always* play a critical role in family caregivers' decisions about the use of available services for an individual with dementia. Some caregivers are so severely burdened that they may have to use *any* available service, regardless of its quality and appropriateness. Other families, even severely burdened ones, may choose not to use an available service even though the service is of high quality and appropriate. For a discussion of some of the reasons why families and other caregivers of people with dementia may be reluctant to use available services, see ch. 3.

Photo credit: Peter Carroll

Because of their strong commitment to their relative with dementia, families are often deeply concerned about the quality and appropriateness of any services they may use for the person.

People's judgments about quality are often impressionistic. With respect to services for people with dementia, someone might observe something about an agency and decide the agency's services are good or not good without thinking about how he or she reached that conclusion. Likewise, someone might hear from a friend, the family physician, or another source that a certain provider is good or not good and accept that judgment as true without questioning its basis.

Impressionistic judgments about quality may be correct, but quality is not necessarily obvious or easy to judge, and people sometimes differ in their impressions about the quality of a particular service. For judgments about quality to be more than impressionistic, they must be based on criteria that are derived from specified goals or desired outcomes of care and from methods of care that are known to achieve those goals or outcomes (174,385,737,832, 925). At present, however, there is no consensus about the goals or desired outcomes of care for people with dementia, and the efficacy of many methods of care has not been proven (482,510,675).

The lack of a consensus about the goals of some services for people with dementia and the lack of proven methods to achieve those goals is not surprising. Although a few agencies and individuals have focused on providing appropriate services for people with dementia for many years, most health care and social service professionals and other providers have only begun to think about the service needs of people with dementia in the past few years, if at all. Moreover, many treatment methods and service interventions that are used routinely for people with other diseases and conditions have not been evaluated rigorously and are simply assumed to be effective (31,832). Services for people with dementia are not unique in this respect.

A major factor that complicates the development of valid criteria to evaluate the quality of services for people with dementia is the current uncertainty about what distinguishes appropriate services for these individuals from appropriate services for people with other diseases and conditions.[4] Many service providers who work with people who have dementia believe that such people have special service needs. The difficulty arises in determining exactly what is or should be different about service goals and methods of care for this patient population.

Over the past decade, as awareness of Alzheimer's disease and other diseases that cause dementia has increased, nursing homes, board and care facilities, adult day care centers, and home care agencies have developed some services specifically for people with dementia. Anecdotal evidence indicates that these "special" services vary considerably. To a great degree, this variation reflects the lack of agreement about goals and methods of care for people with dementia. Box 5-A discusses the variation among special nursing home units for people with dementia, often referred to as "special care units," and points out the difficulty families and others may have in evaluating a special care unit and in determining, for example, whether a given special care unit will provide more appropriate care than a regular nursing home unit for an individual with dementia.

Knowledge about what constitutes appropriate care for people with dementia is constantly evolving, and, in fact, special care units and other specialized services for people with dementia provide ideal

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[4] The *validity* of criteria to evaluate quality refers to the extent to which the criteria measure what they purport to measure (832)

Box 5-A—"Special Care Units" for People With Dementia

Over the past decade, some nursing homes have established "special care units" for people with dementia. One might assume that, by definition, these units would provide appropriate care for people with dementia. Many special care units do provide appropriate care, but anecdotal evidence suggests that some special care units do not provide appropriate care (144,317,321,404,425,482,831). It is said that some nursing homes use the words "special care" as a marketing tool and actually provide no special services for people with dementia. It is also said that some nursing homes with special care units are misinformed about what is appropriate care for people with dementia.

One study of special care units for people with dementia found that the units differed greatly in their goals and methods of care (624). According to the researchers:

> These differences are of such significance that they appear to place special units in direct opposition to each other. Nonetheless, without exception, their proponents have hailed the success of the units (624).

It is easy to understand why families and others who are trying to locate a nursing home for a person with dementia could be confused about special care units. They need a way to evaluate special care units and to compare the units with nursing home units that do not claim to provide special care. Otherwise, some families may unwittingly select a special care unit that provides inferior care or is inconveniently located, when a nondementia-specific nursing home is nearby and provides as good or better care. In this context, the director of a regional Alzheimer's center has told OTA that she knows families who feel guilty about not having placed their relative with dementia in a nursing home with a special care unit, even though the nursing home they chose is nearer to their home and provides excellent care, whereas the nursing home with the special care unit is too far from their home to allow them to visit their relative frequently (55).

Determining whether a given special care unit provides appropriate care for people with dementia would require an answer to the question, "What is appropriate care for people with dementia?" Although there is no consensus about the answer yet, two recently published documents may be helpful to families and others who are trying to evaluate special care units. One is an Alzheimer's Association handbook for caregivers on selecting a special care unit (486). The other is a report on "best practices" in special care units produced by the American Association of Homes for the Aging (60).

These two documents and other publications about special care units provide insight into the components of appropriate nursing home care for people with dementia. Some components of care mentioned in these publications are specific to people with dementia (e.g., the need for staff training in the usual symptoms of dementia and in effective responses to behavioral problems that occur often in this patient population). Other components are not specific to people with dementia and would benefit people with other diseases and conditions as well (e.g., adequate staff-to-patient ratios, avoidance of overmedication, and individualization of care). Greater understanding of what distinguishes appropriate nursing home care for people with dementia v. people with other diseases and conditions is needed to develop valid criteria to evaluate special care units.

SOURCE: Office of Technology Assessment, 1990.

settings for research on alternate methods of care. Nevertheless, the development of criteria to assess quality cannot await final, indisputable evidence about effective methods of care or a consensus about the goals of care for these people. As is true of criteria to evaluate the quality of treatment methods and services for people with other diseases and conditions, criteria to evaluate the quality of services for people with dementia must be developed on the basis of the best available information from research and provider experience, leaving open the option to change the criteria as new knowledge develops.

The following section presents some of the ideas and issues involved in defining and measuring quality. It provides a conceptual framework that could be used to develop criteria for evaluating the quality of services for people with dementia. The subsequent section discusses the potential role of patients and families in defining quality and specifying goals and methods of care.

Defining and Measuring the Quality of Services for People With Dementia

Quality has been defined and its components identified to a greater extent for hospital care, acute medical care, and nursing home care than for home care or social services. It is generally agreed, however, that quality is multidimensional for all these types of services and for all kinds of people who use the services (173,385,831,832). The quality

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of services for people with chronic physical or cognitive impairments has been defined within the dimensions of the person's physical and mental health, functional ability, safety, emotional and social well-being, autonomy, and quality of life (385,563,831). Other dimensions in which quality might be defined are caregivers' well-being and the financial security of the person and his or her family.

To evaluate the quality of a service in other than an impressionistic manner, it is necessary to identify goals or desired outcomes of care within each of those dimensions and to identify methods of care that lead to the specified goals or outcomes. The criteria that are used to measure quality must be derived from the specified goals and methods (174,385,737,832,925).

Specifying Goals of Care

Patients, families, service providers, and others have different goals in the care of people with dementia. The differences reflect their varying backgrounds, values, experiences, and knowledge, their current responsibilities, and their perceptions of the patient's condition. Some people emphasize the importance of maintaining the patient's physical health and safety. Others emphasize autonomy, freedom from fear, or reduced anxiety and agitation. Achieving the best possible quality of life for the patient is probably the overriding goal in the view of many families and some service providers, but the meaning of "quality of life" in this context is highly idiosyncratic (735).

Different goals imply different methods of care and different criteria to evaluate quality. Sometimes legitimate goals of care conflict (385,735). For example, a person with dementia may enjoy walking unattended, valuing control and autonomy in this one area of her life, yet be unsteady on her feet and prone to falls. To ensure her physical safety, her caregivers could prevent her from walking unattended by physically restraining her in a chair, but this decision would conflict with the goal of maintaining her autonomy (831).

Service providers and others often have several goals in caring for a person with dementia. When those goals imply different methods of care in a given situation, priorities must be set, either implicitly or explicitly, in order to determine what good care is in that situation (385). A list of goals in which priorities are not clear is not sufficient to resolve questions about appropriate methods of care in a given situation; nor is such a list sufficient to develop meaningful criteria to evaluate quality.

Identifying Effective Methods of Care

Effective methods of care must be identified in the context of agreed-on goals. In the past few years, many books and articles have been published describing what the author or authors believe are effective methods of care for people with dementia. The goals of these methods of care are sometimes explicit, but often they are not. Moreover, few of the recommended methods have been subjected to rigorous testing (932). Thus, belief in their effectiveness rests primarily on anecdotal evidence. Research to evaluate the effectiveness of alternate methods of care for people with dementia is essential, both to improve services for these people and to develop valid criteria to measure quality.

Developing Criteria To Measure Quality

Criteria for evaluating quality generally pertain to the structure, process, or outcomes of care. *Structural criteria* pertain to the resources available for care (e.g., the number and qualifications of staff, physical plant, and financial resources). *Process criteria* pertain to the activities involved in care (e.g., care planning, medication procedures, and procedures for handling difficult patient behaviors). *Outcome criteria* pertain to aspects of the patient's condition that are attributable to the process of care (e.g., functional ability, participation in activities, and patient satisfaction) (172).

Many commentators use structural, process, and/or outcome criteria to express their answers to the question, "What are good services for people with dementia?" Sometimes, these criteria are presented in the context of goals and methods of care, but often they are not. Families and others may latch onto a single criterion or criteria relevant to only one aspect of care and assume that any service that meets those criteria is good. Thus, for example, some families might believe that a specified physical design ensures that a nursing home will provide high-quality care. Although physical design is an important component of quality, it does not guarantee good care (486).

The structure, process, and outcomes of care are related. Structural criteria are indicators of quality only insofar as the factors they reflect influence the process and outcome of care. Process criteria are indicators of quality only to the extent that the factors they reflect influence outcome, and outcomes are an indicator of quality only if they are attributable to the structure and process of care. It is widely agreed that, by itself, no single structural, process, or outcome indicator is an adequate measure of quality and that all three types of indicators are needed for a valid assessment (173,392,470,755, 832,925).

Information about structure, process, and outcomes may be more or less difficult for families and others to obtain and more or less valuable to them. Information about structural characteristics of a given agency or service provider—e.g., the training and experience of the staff—may be relatively easy to obtain. The exclusive reliance on structural criteria to evaluate quality has been criticized, though, because structural characteristics indicate only the *capacity* of the agency or provider, not the services that are actually given (173,734).

Accurate information about the process of care—i.e., the activities involved in care—may be difficult for families and other outsiders to obtain, in part because they may not have an opportunity to observe the process of care directly before they make a decision to use the service. Survey procedures for government regulation of nursing homes and other agencies and for voluntary accreditation programs include process criteria and may produce findings that are useful for families and others who are trying to evaluate the quality of services for a person with dementia. Some processes that are selected for observation or regulation for these purposes are not linked or are only indirectly linked to the goals or desired outcomes of services (563,831). Thus, they may not be valid indicators of quality. A later section of the chapter discusses the availability of findings from regulatory and accreditation programs and their potential value for people who are trying to evaluate services.

Recognition of the limitations of structural and process criteria and concern about the impact of cost containment on the quality of many types of services have spurred new interest in outcome criteria (392,470,925). Accurate information about the outcomes of services provided by different agencies and individuals might be valuable to families and others who are trying to select the best service provider. For most of the types of services that may be needed for people with dementia, outcome measures are only beginning to be used. Thus, information about patient outcomes is not generally available.

Moreover, information about patient outcomes, like information about structural and process indicators, may be difficult for families and others to interpret correctly. The use of outcome criteria to measure quality of care assumes a direct link between the process and outcomes of care, but that link is seldom simple or clear. Obviously, outcomes that are not attributable to the process of care should not be used to assess its quality (174,311,471).

Many factors other than the process of care can affect patient outcome. These include the severity of the person's condition, the course of his or her disease(s), and the ability and willingness of the patient and family to cooperate with the process of care. Because these factors affect outcome independently of any service, high-quality care does not always produce good outcomes (392,755). Likewise, good outcomes may occur even if the quality of care is poor.

Lastly, the use of outcome criteria to assess quality requires a comparison between expected outcomes and achieved outcomes. At present, very little is known about the course of many diseases that cause dementia, and people with dementia vary greatly in the progression of their symptoms.[5] As a result, it is often difficult to judge whether observed changes in a patient's condition over time are the result of services the patient received or an inevitable consequence of his or her underlying disease. As more is learned about the normal course of diseases that cause dementia, it will become easier to identify valid outcome criteria to evaluate the quality of services.

What Role Should Patients and Families Play in Defining Quality and Specifying Goals and Methods of Care?

Historically, what constitutes good care has been defined by the providers of care (471,831,832). Goals, methods of care, and criteria for evaluating quality have been established by health care and social service professionals and other service providers and reflect their point of view. Some commentators argue that patients should play a greater role in defining quality (130,737). Opinions on this issue vary and may depend on the kinds of patients and services that are being considered.

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[5] This topic was discussed at greater length in ch. 1.

For many people, the need for medical care and other health-related services is episodic and distinct from their daily lives, and the services they receive are intended to cure specific illnesses or solve other health-related problems. For people with dementia and other chronic debilitating conditions for which medical cures and complete solutions frequently are not possible, health-related and social services may be needed over a prolonged period and may become interwoven with the life of the patient and patient's family (if there is one). Services provided in a patient's home often involve intimate details of the patient's life (386). At the extreme, in a nursing home, the care and the life of a patient may almost merge (120,385).

In such situations, the quality of care and the quality of the patient's life may be barely separable—and enhancing the quality of the patient's life may become the most appropriate goal of services. People's views about quality of life differ, however. If enhancing the patient's quality of life is the primary goal of care, some commentators suggest, then patients' values and preferences should be reflected in the definition of quality of care (392). Many commentators go further, suggesting that patients' values and preferences should be reflected in the definition of quality of care even if quality of life is not the primary goal of services (174,471,768). In fact, some commentators would probably consider the responsiveness of a service provider to patients' values and preferences itself to be an important indicator of the quality of care.

Patients' values and preferences can be reflected in the definition of quality of care in a number of ways. They can be taken into account in establishing the goals of care, in setting priorities among the goals, or in selecting among alternative methods of care (74). Criteria for evaluating quality can also be chosen to reflect patients' values and preferences (470). One outcome indicator that measures quality in relation to the patient's values and preferences is patient satisfaction. The importance given to other outcome criteria can be adjusted to reflect patients' values and preferences (130).

If a person is severely cognitively impaired or unable to communicate, ascertaining that person's values and preferences may be difficult or even impossible. In some cases, the best way of ascertaining the person's values and preferences is to consult his or her family and friends about what the person would have considered good care. Some commentators would probably want to limit the role of a demented person's family in defining good care to representing the person's values and preferences. Other observers might argue that the values and preferences of a demented person's family are relevant to determining what constitutes good care.[6]

An underlying assumption of this OTA study is the importance of supporting family caregivers. In some cases, supporting family caregivers means giving them the information they need to evaluate different care options (919). Supporting family caregivers also may mean giving them a greater role in defining quality and specifying goals and methods of care. Several approaches for expanding families' role in monitoring and controlling the quality of services provided for their relative with dementia are discussed later in this chapter.

Apart from consulting a person's family and friends, another way of ascertaining the values and preferences of a person with dementia is to use a "values history." A values history is a document that expresses a person's wishes, values, and preferences with respect to his or her care. The Institute of Public Law at the University of New Mexico has developed a values history document for elderly people as part of its "National Values History Project" (252). The document is currently being tested in hospitals, nursing homes, home care agencies, and other sites. Recently, the Institute of Public Law completed a project in which volunteer "temporary treatment guardians" successfully used values histories to ascertain the wishes and preferences of hospitalized elderly people who were too cognitively impaired to make decisions about their own care and had no relative or friend to make the decisions for them (802). Although the values history document focuses on medical treatment decisions, it does include questions about a person's attitudes about independence, self sufficiency, and control and about his or her living situation, finances, and relationships with relatives and friends who might be involved in decisions about the person's care.

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[6] Some of the issues that arise in balancing the values and preferences of a demented person and the person's family are discussed at greater length in ch. 4.

LIMITATIONS OF POSSIBLE SOURCES OF INFORMATION

Given the complexity of the issues involved in evaluating the quality and appropriateness of services for people with dementia, just discussed, it would certainly be easiest for a federally mandated linking system *not* to concern itself with the quality and appropriateness of services to which it connects people with dementia and instead to rely on families and other informal caregivers to obtain for themselves the information they need to evaluate services. Many books, pamphlets, and articles that offer advice to families and other informal caregivers about how to obtain services for a person with dementia suggest that caregivers are responsible for selecting good services. The publications point out that identifying good services takes time and that caregivers may have to make many calls to find someone who can help them identify good services. Many of these publications recommend that caregivers of people with dementia start looking for services and visiting facilities before they need them (15,133,319,517,767).

The publications suggest that information about the quality and appropriateness of services—on which caregivers could base their selection of services—may be available from one or more of the following sources:

- relatives, friends, and acquaintances who have used a service;
- physicians, nurses, social workers, and other health care and social service professionals;
- professional and provider associations (e.g., the State or local medical society, or nurses, hospital, or nursing home associations);
- the Alzheimer's Association;
- caregiver support groups;
- "dementia experts";
- agencies that provide telephone information and referrals;
- hospital discharge planners and case managers;
- State long-term care ombudsmen;
- aging network agencies (e.g., the State office on aging, area agency on aging (AAA), or a senior center);
- other State and local government agencies (e.g., offices of the State departments of health, mental health, human services, social services, or public welfare);
- government regulatory agencies;
- voluntary accreditation programs;
- internal quality assurance programs; and
- other possible sources of information (15,38, 133,464,527,767).[7]

OTA's review in this section considers each of the potential information sources listed above in terms of two questions:

- whether information about the quality and appropriateness of services for people with dementia is likely to be available from the source, and
- if so, whether the information is likely to be accurate and/or helpful to families and others who are trying to locate good services for a person with dementia.

Many people whom OTA asked about how families and others can obtain information about the quality and appropriateness of services for people with dementia said that families and other informal caregivers should not be expected to obtain the information themselves, and that such an expectation places too great a burden on many families. Whether expecting families and other informal caregivers to obtain information about the quality and appropriateness of services places too great a burden on them depends partly on how difficult it is to obtain the information and partly on characteristics of the family or other caregiver and the circumstances in which they are trying to locate and arrange services. For some families and other informal caregivers, the approach to obtaining information about quality and appropriateness that is recommended in most advice books and pamphlets—contacting a variety of people and agencies, asking questions, and visiting potential service providers—may work reasonably well. It is easy to imagine numerous reasons why this approach would not work well for many other families and informal caregivers, however, and these reasons are discussed in the section of this chapter that considers limitations on caregivers' abilities to obtain information about quality and appropriateness. This section focuses only on the availability and accuracy of information about quality and appropriateness from specific sources.

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[7] It is not always clear whether the publications that recommend some of these sources are suggesting them as sources of information about what services are *available* or about what services are *good*. Readers of these publications probably assume, however, that at least some of the recommended sources of information will be able to provide information about quality and appropriateness.

The information about quality and appropriateness that families and other informal caregivers need to make informed decisions about services should also guide decisions about services for people with dementia who have no informal caregiver. It is unclear, however, who would use the information and what would happen to people with dementia for whom no acceptable services could be found. These questions are discussed later in this chapter.

The reader should bear in mind that the conceptual and practical difficulties in defining and evaluating quality that were discussed in the previous section of this chapter are applicable to any information about quality that may be provided by the sources discussed here. In the following discussion, those difficulties are assumed to exist and are not repeated for each source.

Relatives, Friends, and Acquaintances Who Have Used a Service

Relatives, friends, or acquaintances who have used a service are a possible source of information about its quality. They have first-hand experience with the provider, and to the extent that their needs are or were similar to those of the patient for whom services are being sought, their judgments about quality may be accurate and helpful.

The story of Mrs. D in chapter 1 includes an instance in which advice about the quality of a service provider that was offered by a chance acquaintance proved helpful. One of Mrs. D's sons who called the local AAA happened to talk to a secretary there whose mother had Alzheimer's disease. The secretary had used a local adult day program for her mother and recommended it highly. Mrs. D's sons visited the center and agreed with her assessment.

Although the advice of a chance acquaintance proved helpful in Mrs. D's case, there are several drawbacks to relying on relatives, friends, or acquaintances for judgments about the quality of services. One is that relatives, friends, and acquaintances may not know anyone who has used a provider of the type that is needed. Another is that the judgments of friends and acquaintances may reflect values and preferences of one family or patient that are not shared by another family or patient (767). A patient's condition and care needs and specific aspects of the patient's caregiving situation differ from one patient and family to the next, so that what is good for one patient and family may not be equally good for another patient and family.

Another drawback to relying on judgments about the quality of services that are made by relatives, friends, and acquaintances is that such judgments may be based on observations of a single aspect of an agency's services or an isolated incident that does not reflect the quality of the services in general. A family may think highly of a nursing home, for example, because they feel close to one staff member who has been friendly or kind, even though the care provided by the nursing home is not particularly good overall.

Another drawback is that information about quality that is obtained from relatives, friends, or acquaintances may be based on outcomes that are not attributable to the process of care and thus not valid indicators of quality. The physical and mental deterioration of a person with dementia is distressing to everyone involved, and families may have difficulty separating their feelings about the patient's condition from their feelings about the service provider. A family whose relative dies in a nursing home after a long, difficult illness, for example, may have negative feelings about the facility, even though the patient's deterioration and death were caused by his or her illness, not poor care.

A final drawback to relying on the opinions of relatives, friends, or acquaintances about the quality of services is that such individuals are likely to have had experience with only one or two service providers. Although they may offer correct information about those providers, they are unable to assist the caregiver in comparing the quality of services offered by other providers.

Physicians, Nurses, Social Workers, and Other Health Care and Social Service Professionals

People are used to relying on their physician for referrals to medical and health-related services (832). For many people, relying on a physician may be the easiest and most comfortable way to get the name of a good service provider. Ideally, a physician who has a long-standing relationship with a patient and family can match what he or she knows about them and what he or she knows about service providers in the community and recommend the best provider for them.

This ideal often does not work in practice. Families report that many physicians are not knowledgeable about the kinds of services that dementia patients are likely to need and that some physicians are not willing to spend time talking about services (125,257,412,531).[8] Physicians' knowledge of community services is derived in part from feedback they receive from patients and families they refer to various providers. Physicians who have many patients with dementia may be more likely than those with few demented patients to know about the quality of relevant services.

Some people have a tie to a nurse, social worker, psychologist, or other health care or social service professional who might be knowledgeable about the quality and appropriateness of services. Like physicians, these professionals have different areas of expertise and serve different kinds of clients. Some have extensive experience with community agencies and providers who serve people with dementia, whereas others may have never even visited a nursing home, adult day center, or other agency (390).

Health care and social service professionals usually have professional contacts that are a potential source of information about quality that generally is not available to families or other informal caregivers. In addition, because of their training, health care and social service professionals have a frame of reference for evaluating quality of care that most families do not have. On the other hand, individual physicians, nurses, social workers, or other health care and social service professionals are unlikely to have a systematic method for evaluating quality. As a result, their judgments about quality, although grounded in professional training and experience, still are impressionistic.

It takes time for anyone to become familiar with community agencies and service providers. Health care and social service professionals who are new to a community may know very little about the quality of available services.

Lastly, some health care and social service professionals are affiliated with service providers in such a way that they benefit financially from referrals, and some of them routinely refer patients or clients to those providers even if they know that better services are available from other providers. It is not known how often this practice occurs.

For all the reasons just mentioned, health care and social service professionals are likely to differ greatly in their ability to provide helpful information about the quality of services. In light of this difference, a question that arises is: How can patients, families, and others know which professionals are most likely to be helpful? Another question that arises is: When a specific physician or other health care or social service professional gives a caregiver the name of, say, a home care agency for a person with dementia, how should the family interpret the referral?:

- Does the referral mean that the agency is one that the professional recommends on the basis of his or her extensive knowledge about the quality of care provided by various home care agencies in the community?
- Does it mean that the agency is one that the professional knows about and regards as good, although he or she is not familiar with other agencies in the community?
- Does it mean that the agency is one that the professional knows very little about?
- Does it mean that the agency is one with which the professional has some financial affiliation?
- Does it mean that the professional is referring the patient to the agency not because of the quality of its care but because he or she knows the agency will accept the patient's source of payment?
- Does it mean that the professional is referring the patient to the agency not because of the quality of its care but because he or she knows that the patient will be difficult to care for, and, for the sake of future referrals, he or she wants to maintain a good relationship with agencies that provide better care?

Patients, families, and others may very well assume that a referral from a physician or another health care or social service professional implies at least some endorsement of the agency or provider, and therefore they may not question the basis for the referral. They also may not question referrals because they think it would be disrespectful to the professional or because they do not know what to ask.

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[8] For further discussion of this topic, see ch. 2.

Some health care and social service professionals routinely give patients or families the names of three service providers in order to give them a choice. Given the different knowledge and motivation of professionals, the meaning of three referrals is no more clear than the meaning of one referral:

- Should the patient or family assume the first name on the list is the one the professional really recommends?
- Might all three choices be good, or all three poor?
- Does a list of three providers imply anything about quality?

In summary, referrals to service providers by individual health care and social service professionals may or may not indicate that the providers offer good care. Patients, families, and others are unlikely to know this, and without knowing it, they cannot function as informed consumers in selecting services.

Professional and Provider Associations

Medical societies, nurses' associations, and associations of other professionals and providers may be good sources of information about what services are *available*. These organizations can often provide lists of their members in a certain area or members who say that they specialize in caring for certain types of patients. Some also refer patients and families to individual association members.

These lists and referrals generally are not evaluative however. They simply indicate that the individual provider or agency belongs to the association. Except to the extent that belonging to a given association or having been certified by such an association is evidence of quality, the lists and referrals do not provide information about quality.

The Alzheimer's Association

Advice books and pamphlets for caregivers of people with dementia often advise caregivers to contact the Alzheimer's Association for information about services. Many of these publications imply that the Alzheimer's Association—or more likely one of its local chapters—will be able to provide information about quality. One Alzheimer's Association pamphlet says, for example:

> Once you have located a service, you will want to evaluate its quality and appropriateness to your needs. Here again, your local [Alzheimer's Association] chapter, whose members have gone through this experience before you, can be of great help (15).

As discussed in chapter 8 of this report, information and referral is one of the primary functions of Alzheimer's Association chapters, but chapters vary in the manner in which they perform it. In 1988, an OTA contractor surveyed 10 Alzheimer's Association chapters by telephone to learn about their information and referral services (484). The chapters were chosen to represent a range of sizes, urban/suburban/rural location, and the use of professional v. volunteer staff. Among other questions, the chapters were asked, "How do you determine the quality of services to which you refer patients and families?" Chapter respondents reported that they use three methods to determine quality:

- informal communication with other agencies;
- advice from professionals on their board; and
- feedback from families.

One chapter respondent said, "This is a small town. I know most of those places" (484).

None of the 10 chapters had a systematic way of collecting information about the quality of services. Most of the chapters reported that if they receive negative feedback from a family about an agency or provider, they "check it out" and remove the agency or provider from their referral list if they conclude that the services are inadequate (484). One chapter keeps a file box of families' comments about service providers and makes the box available to other families (485). None of the chapters reported routinely asking families about the quality or appropriateness of services they had used. Two of the chapters reported that they ask service providers if they have a license and whether their staff is trained to work with dementia patients. One chapter has a list of nursing homes that have failed government inspections (484).

In the opinion of the OTA contractor who conducted the survey and who has visited many Alzheimer's Association chapters in addition to those surveyed, the informal methods that chapters use to evaluate quality usually work well and chapters generally know which agencies and individuals provide good care for people with dementia (484). She concludes that relying on an informal process works as long as the network of providers and users remains small and the chapter knows the providers and the families and professionals who give it information and feedback. As the network of providers and users expands, however, it becomes more difficult for chapters to maintain accurate information about quality (484).

The Southeastern Wisconsin Alzheimer's Association Chapter is currently under contract to the State of Wisconsin to provide statewide information and referral services for Alzheimer's patients through the Alzheimer's Information and Training Center.[9] It has created a computerized database of service providers that is used to give callers information about services in their geographic area (410). According to the Southeastern Wisconsin chapter's education coordinator, how to provide information about quality is "a big question" (263). Callers are given three choices of service providers, if there are three choices. They are told that there are important differences in the quality of services offered by different providers, and they are urged to visit agencies and talk to providers before choosing one. Callers are not told which agencies or providers give good care. The chapter believes that it must be "unbiased," partly because of concerns about legal liability. It believes, for example, that callers must be given the names of all the nursing homes in a locality that have a "special care unit," not just the name of one facility that the professional staff or volunteers think is good.

Some Alzheimer's Association chapters give out printed materials with advice on selecting a particular kind of provider. Figure 5-1 is a list of questions for evaluating an adult day care center distributed by the Cleveland Alzheimer's Association Chapter.

The Greater Washington, DC Alzheimer's Association Chapter has a video for families to watch about how to select a nursing home (232). The chapter also has a list of members who have a relative in a local nursing home or board and care facility and are willing to talk to other families about the facility.

Caregiver Support Groups

Caregivers who attend support groups sponsored by the Alzheimer's Association and other public and private agencies often obtain first-hand information from other caregivers about the quality and appropriateness of services they have used. Research indicates that participation in a support group leads to increased knowledge about community services (245) and that this aspect of participation in a support group is valued by group members (294).

Many caregiver support groups devote meetings or parts of meetings to discussions about community resources (377). In relatively informal support group meetings, outside experts may share their observations about the quality and appropriateness of services offered by community agencies and providers more freely than they would in a more formal or public situation. The leaders of support groups may also be knowledgeable about community services and willing to share their judgments about quality and appropriateness, either during meetings or in personal discussions later on (256).

The primary drawback to relying on caregiver support groups as a source of information about the quality and appropriateness of services is that many caregivers do not belong to support groups. Male caregivers, ethnic minority group caregivers, and caregivers who have no one to care for the patient while they attend a meeting are particularly unlikely to belong (158,314).

"Dementia Experts"

"Dementia experts"—individuals who develop or work in programs designed for people with dementia or who serve many people with dementia—are likely to have opinions about the quality and appropriateness of community services based on information from their own clients who use, or have used, the services. Furthermore, in those communities with only a few agencies providing services specifically for people with dementia, the service providers are likely to know each other, to participate in planning any new service for people with dementia, to be on the board of the local Alzheimer's Association chapter, to run support groups, and/or to provide training about dementia for the staff of nursing homes and other community agencies.

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[9] For more information about the Alzheimer's Information and Training Center operated by the Southeastern Wisconsin Alzheimer's Association Chapter, see box 8-G in ch. 8. Additional information is provided in the section on State information and referral programs in ch. 7.

Figure 5-1—List of Questions for Evaluating an Adult Day Care Center, Distributed by the Cleveland Alzheimer's Association Chapter

A.D. Alzheimer's Disease
and Related Disorders Association, Inc.

Cleveland Chapter 1801 Chestnut Hills Drive Cleveland Heights, Ohio 44106 Phone: 216-721-8457

EVALUATING DAY CARE SERVICES

Here is a handy checklist of questions to help you ascertain how well a facility is equipped to fill its goal of providing respite for caregivers:

- Is it convenient and accessible?
- Does it provide or arrange for transportation?
- Does it provide or arrange for companion/aid assistants to help the care-receiver get up bathed, dressed and ready?
- Are its service hours appropriate for your situation?
- Do its services include family-supportive programming such as caregiver support groups or referral services?
- How expensive is it?
- Is there financial assistance available?
- Are there any hidden expenses, such as lunch fees, craft supply fees, fees for outings?
- Are there any hidden benefits, such as the availability of regular professional testing for blood pressure, annual immunizations, hair styling services, dental check-ups, etc.? (Although such benefits will typically require additional fees, they may be invaluable time-savers for caregivers.)
- Must you commit to a minimum amount of service, i.e., at least 2 days/week?
- What is the notification policy for absence due to illness or scheduling problems?
- What is the policy concerning late arrival or late pick-up?
- What are the notification policy and conditions for terminating service?

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Figure 5-1—List of Questions for Evaluating an Adult Day Care Center, Distributed by the Cleveland Alzheimer's Association Chapter—Continued

Here is a handy checklist for ascertaining how well a facility is equipped to meet the needs of your loved one:

- Does it perform a comprehensive assessment prior to placement, including an evaluation of the client's medical needs, social and family history, cognitive functioning, and social skills?
- Does it restrict or segregate its population by types of impairment or by level of care required?
- What is the ratio of staff to client? (Remember, a new facility is likely to increase its participants over time; ask for the existing ratio, as well as the worst case ratio.)
- What training, education, and practical experience does the staff have in dealing with care-receivers whose needs are comparable to those of your loved one?
- Is there a formal process for reviewing a client's needs and evaluating a client's participation on a regular basis?
- Is there an accessible and easy-to-talk-to person available to discuss your loved one's special needs, level of participation, etc., when problems or questions arise?
- Can the facility accommodate the special physical or medical requirements of your loved one, i.e., can it:
    - dispense medicine?
    - give reminders about taking pills?
    - assist with toileting?
    - provide total access and participation to wheelchair-restricted client?
    - effectively communicate with hearing impaired participants?
- Does the client population appear to be compatible with your loved one's social history? (Some men are uncomfortable with an overwhelming female group; some people are intolerant of racial and ethnic differences. Unless you are honest about the realities of your loved one's social history, a lasting and effective placement will be impossible.)

BEST COPY AVAILABLE

Figure 5-1—List of Questions for Evaluating an Adult Day Care Center, Distributed by the Cleveland Alzheimer's Association Chapter—Continued

- Are there specific behaviors or care needs which would enforce your loved one's withdrawal from the program? (Since Alzheimer's disease is a progressive disorder, you need to find out not only how a facility is going to handle existing care needs, but also whether they are prepared and able to handle potential ones, i.e., can they accommodate:
    - incontinence?
    - difficulties in speaking?
    - wandering?
    - special dietary requirements?
- Are the programs and activities adult appropriate?
- Does the programming include activities suitable to your loved one's social history and capabilities, i.e.:
    - gardening?
    - outdoor activities?
    - cultural activities?
    - music therapy?
    - physical therapy?
    - travel movies?
    - joint activities with children?
    - productive work, i.e., social service projects or work-for-pay?
    - homemaker crafts?
- How does the staff handle a client's unwillingness to actively participate?
- Are meals nutritious and attractively prepared?
- Are the staff and facility neat, clean, and orderly in appearance?
- Are there programs/activities which involve families?

SOURCE: J.F. Durante, "Evaluating Day Care Services," Cleveland Alzheimer's Association Chapter, Cleveland OH, no date.

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Photo credit: Bill Adams

Caregivers who attend support groups often are able to obtain first-hand information about the quality and appropriateness of services from other support group members.

Anecdotal evidence suggests that these "dementia experts" often provide accurate and helpful information about the quality and appropriateness of services to families and others who are lucky enough or persistent enough to reach them. As the network of service providers and users expands in a community, however, "dementia experts" may become concerned about legal liability and thus increasingly reluctant to recommend specific service providers, especially to people they do not know.

Agencies That Provide Telephone Information and Referrals

Agencies whose primary function is to provide telephone information and referrals generally maintain a list of community agencies and providers that includes the services they offer and sometimes their area of specialization, service hours, eligibility requirements, fees, etc. Telephone information and referral agencies often give callers the names of several agencies or providers from their list, but they usually do not recommend specific providers. If their list, which is usually compiled from information supplied by providers, includes a category of services for people with dementia, they can give callers information about which providers say they offer such services.

In 1988, OTA contractors surveyed agencies in Cuyahoga County, Ohio, to determine what services they provided for people with dementia and interviewed representatives of 24 agencies that reported providing information and referrals for people with dementia (186).[10] Only 1 of the 24 agencies was primarily an information and referral agency; the others were agencies that provide information and referrals in conjunction with their other functions. None of the agencies had systematic procedures for evaluating the quality of services to which they referred clients. Most of the agency representatives said that agency staff members form opinions about the quality of various services in the process of arranging and monitoring services for their clients and through informal discussions with colleagues both inside and outside the agency (186). When the agencies receive telephone requests for information about services, agency staff members respond on the basis of opinions formed in those ways.

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[10] Most of the findings of the survey and interviews in Cuyahoga County, Ohio, are discussed in ch. 2. A full report on the study conducted for OTA in Cuyahoga County is available from the National Technical Information Service in Springfield, VA (see app. A).

OTA's contractors concluded that the telephone referral process usually works satisfactorily—i.e., the agencies usually give callers the names of providers they know about and regard as good (186). The criteria agency staff use to evaluate quality are not known, however, and their judgments about quality may or may not be correct. Moreover, some agency staff members believe that the services of for-profit providers are not as good as the services of nonprofit providers and rarely refer callers to for-profit providers. Lastly, some agency staff members do not know about new services. In this regard, OTA's contractors noted that providers of new services for people with dementia often complain that agencies always refer callers to the old providers and it is difficult for a new provider to "break in" regardless of the quality and appropriateness of its services (185).

Hospital Discharge Planners and Case Managers

A major function of all hospital discharge planners and case managers is linking people with services. In the process of performing this function and through feedback from patients and families, discharge planners and case managers form opinions about the quality of services offered by various community agencies and individual providers.

Published practice guidelines for hospital discharge planners and case managers emphasize the importance of identifying high-quality services for clients and of involving clients and families in selecting services. The American Hospital Association's "Guidelines for Discharge Planning," for example, state that hospital discharge planners should identify "resources needed to assure high-quality post-hospital care" and "develop with patients and their families appropriate discharge plans" (20).

The American Nurses' Association's guidelines for nursing case management state that one of the goals of case management is "the provision of quality health care" and that an important function of the case manager is "linking the client with appropriate service providers" (22). The National Association of Social Workers' publication "Standards and Guidelines for Social Work Case Management for the Functionally Impaired" stresses that case managers should support informed client decisionmaking:

> The case manager must assure that each client receives appropriate assistance by providing the client with accurate and complete information about the extent and nature of the services that are available and by helping the client to decide which services will meet his or her needs (572).

Given their involvement in linking patients to services and practice guidelines such as those just mentioned, one might expect that hospital discharge planners and case managers would be a good source of information about the quality and appropriateness of services. On the other hand, hospital discharge planners and case managers are unlikely to have a systematic method for evaluating quality. Consequently, their judgments about the quality of services may or may not be accurate. Furthermore, some hospital discharge planners and case managers are not knowledgeable about dementia and therefore have no basis for determining whether a given service is appropriate for people with dementia. Even hospital discharge planners and case managers who are knowledgeable about dementia may not be

Photo credit: Cleveland Chapter of the Alzheimer's Association.

Concerns about legal liability and organizational pressures limit the ability of some hospital discharge planners and case managers to provide families and others with information about the quality and appropriateness of services they may use for a person with dementia.

a good source of information about the quality and appropriateness of services for people with dementia, however, because of the concerns about legal liability and organizational pressures that are discussed below.

Concerns About Legal Liability

A 1987 legal memorandum of the American Hospital Association answered the question, "To what extent, if any, can hospital discharge planning personnel recommend, endorse, or steer discharged patients to particular post-hospital facilities and services?" in the following way:

> It is *not* the discharge planner's responsibility to recommend or endorse particular after-care facilities to patients; indeed, such recommendations or endorsements can expose both the hospital and hospital employees who participate in the discharge planning process to legal risks (21).

According to the 1987 legal memorandum, a hospital can be liable for negligence for referring a patient to a facility or service if the patient is injured in some way there and the possibility of the injury could have been foreseen by hospital staff:

> The likelihood of liability is increased when hospital discharge planning personnel go beyond simply advising, notifying, or informing a patient of his options, and affirmatively recommend or endorse a particular option. A recommendation or endorsement suggests that hospital personnel have investigated the facility according to objective, uniform criteria; are in possession of all information necessary to evaluate reasonably foreseeable risks to the patient if the referral is made; and have determined that the particular facility meets the patient's needs (21).

According to the 1987 legal memorandum, followup telephone calls by discharge planners to patients or families to ensure that their discharge plan is working also expose the hospital to liability for negligence, because such calls may imply that the hospital is still responsible for the patient's care (21).

To minimize legal risks, the American Hospital Association's memorandum advises that hospital discharge planners should not decide on their own to make recommendations about post-hospital services or followup calls to discharged patients (21). Rather, hospitals should establish general policies for discharge planners to follow in all but exceptional cases, and they should designate a person to make decisions about cases in which there may be some reason for deviating from those general policies.

OTA has no information about how often hospital discharge planners recommend specific service providers based on judgments about their quality. Certainly, the concepts expressed in the American Hospital Association's 1987 legal memorandum would discourage discharge planners from making such recommendations.

That case managers may also be legally constrained from making recommendations about service providers based on judgments about their quality is suggested by the decision in a 1987 Oregon case *Bionic Health Care, Inc.* v. *State of Oregon Department of Human Resources, et al.* (70). Case managers in a public agency had stopped referring clients to one nursing home that they believed was providing poor care and that was under review by the State licensing and certification agency. The nursing home sued, arguing that it had a valid State license and was certified by Medicare and Medicaid and that the case managers could not refuse to refer clients there. The nursing home won, and the case managers have been instructed not to make recommendations to clients about service providers (435).

Again, OTA has no information about how often case managers recommend certain service providers on the basis of quality. One member of the advisory panel for this OTA assessment, who interviewed case managers who refer people to nursing homes, found that the case managers generally believed that they were legally constrained from making recommendations about nursing homes based on quality. The panelist went on to comment that clients and their families generally don't know this (389).

People who make nursing home referrals in some other countries may not be so constrained. In Australia, for example, groups of health care and social service professionals "blacklist" nursing homes they believe provide poor care and do not refer clients to these facilities; as a result, the facilities are forced to improve the quality of care they provide or risk going out of business (273). The blacklisting is not capricious, however; grounds for the decisions are identified systematically, in case the decisions are challenged (485).

Organizational Pressures

Organizational pressures also restrict some hospital discharge planners and case managers from making referrals on the basis of quality. Case managers employed by agencies that provide services in addition to information and referral and case management are often expected to refer clients to their own agency's services rather than services provided by other agencies, irrespective of the quality of the services (186,386). Furthermore, some agencies have formal agreements with other service providers, and case managers employed by those agencies are expected to refer clients to those providers, irrespective of the quality or appropriateness of the services.

Organizational pressures to complete care plans quickly also constrain discharge planners and some case managers from making referrals on the basis of quality. Medicare's prospective hospital payment system, instituted in 1983, creates strong financial incentives for hospitals to reduce patients' length of stay. Discharge planners are under pressure to make plans for patients' post-hospital care quickly and may not have time to arrange the best available services (209,947). Moreover, some high-quality services may not be available at the time a patient is discharged from the hospital.

Case managers who are required to arrange services within cost limits may be severely restricted in their ability to make referrals on the basis of quality. The case management literature is replete with discussions of the conflict between the role of the case manager as an advocate for the client, trying to ensure that the client receives good services, and the role of the case manager as an administrator of resources, trying to ensure the cost-effective use of limited services (48,175,230,382,893). In one role, the case manager is seen as the agent of the client and, in the other, the agent of the agency or system.

Some commentators argue that the two roles—client advocate and resource administrator—are not necessarily incompatible if case management is seen as serving an entire population at risk and attempting to meet the needs of that population within available resources (384,892). As noted in chapter 3, a study of 127 case managers in Oregon and Washington State found that the case managers did not perceive the two roles to be in conflict (47). But the theory and practice here are from the point of view of the system, not the client. If there were more than one provider of a certain type of service in a community, and case managers gave patients and families accurate information about the relative quality of the services, it is hard to imagine why some patients and families would accept poor-quality services, knowing that other patients and families were receiving better services (assuming, of course, that the patients and families were equally able or unable to pay for the services).

Most private geriatric case managers are not subject to the organizational constraints discussed above and may therefore be able to provide information about their perceptions of the quality of services offered by various providers. Some private geriatric case managers visit or interview most of the agencies and providers to whom they refer their clients (357,450). On the other hand, hiring a private geriatric case manager can be costly and thus not a realistic option for many patients and families. In addition, some private geriatric case managers provide certain services themselves and may not give clients information about other providers of these services (390).

OTA's advisory panel and consultants for this study agreed that *at the very least*, the staff of agencies that are designated to constitute a national linking system for people with dementia should disclose to their clients any legal or organizational factors that limit their ability to give clients accurate information about the quality and appropriateness of services or to make referrals on the basis of quality. Beyond that, perhaps ways could be found to enable the staff of agencies that constitute the linking system to provide their clients with information about the quality and appropriateness of services and to connect their clients to what they consider the best available services.

State Long-Term Care Ombudsmen

The Older Americans Act mandates that every State have a long-term care ombudsman to investigate and resolve complaints of residents of nursing homes and other residential care facilities. The long-term care ombudsman program is implemented differently in different States, but it is clear that State long-term care ombudsmen and local paid ombudsman employees and volunteers are knowledgeable about the quality of services provided by long-term care facilities. They generally will talk to families and others about the services provided by different nursing homes and board and care facilities, and many of them seek opportunities to talk to individuals or groups about steps to take in selecting a facility. They usually do not specifically recommend one facility over another. Some ombudsmen tell callers whether they have had complaints about a facility and, if so, what the subjects of the complaints were and whether the facility cooperated in resolving them (561,629). Other ombudsmen are more cautious about giving out such information.

One drawback to relying on State long-term care ombudsman programs for information about the quality of nursing homes and other residential care facilities is that many people are not aware of their State program, and families may not know how to contact the ombudsman. In addition, ombudsman programs in many States are underfunded and understaffed to take on the job of helping people choose good facilities. Lastly, some ombudsmen may not be knowledgeable about dementia and therefore may have no basis for determining whether a given facility provides good care for people with dementia.

The Robert Wood Johnson Foundation is currently funding an "Ombudservice" for home care clients through the Community Council of Greater New York (140). Like State ombudsman programs, the Ombudservice focuses on resolving client complaints—in this case, complaints of people receiving Medicaid-funded personal care services. In the process of investigating complaints, the program accumulates information about the quality of various personal care providers, but that information is not currently available to the public (561).

Aging Network Agencies

Aging network agencies include State units on aging, area agencies on aging (AAAs), senior centers, and other agencies that receive Older Americans Act funds.[11] Books and pamphlets that advise families about how to locate services often recommend that they contact such agencies for assistance. Although aging network agencies vary greatly, most of them will give families a list of service providers. In addition, many aging network agencies distribute written materials on how to select a provider, and some offer case management to help people locate and arrange services.

In any of these agencies, a family might find someone who knows about community services and is willing to share his or her opinions informally about the quality of services offered by different providers. OTA is not aware of aging network agencies that have a systematic method for evaluating service providers or giving families and others information about their relative quality.

Other State and Local Government Agencies

In some States, State and local offices of the departments of health, mental health, human services, social services and/or public welfare, and regional or local health planning agencies have lists of providers, their services, and their practice specialties, which can be requested by anyone. People may also be able to find out from one or more of these agencies whether certain providers are licensed and to obtain the results of government inspections of facilities. The agencies are unlikely to provide other information about the quality of specific service providers. As with aging network agencies, however, families may be able to find someone in any of the agencies who is knowledgeable about providers and willing to talk informally about their quality.

Government Regulatory Agencies

Various government agencies regulate health care, long-term care, and other services that may be needed for people with dementia:

- State agencies license individual professionals and nonprofessional service providers (e.g., physicians and home health aides).
- State and local government agencies license health care and long-term care agencies (e.g., nursing homes and home health care agencies).
- Federal and State Medicare and Medicaid agencies certify facilities and service providers that receive reimbursement from Medicare and Medicaid, and they contract with peer review organizations (PROs) to review the hospital care and some nursing home and home health care provided to Medicare and Medicaid beneficiaries.

Each of these regulatory agencies has several purposes, one of which is to safeguard quality of care.

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[11] For more information on aging network agencies, in particular AAAs, see ch. 8.

If government regulation guaranteed that all services were at least adequate, families and others would not have to worry about basic aspects of quality and could concentrate instead on finding services that matched the individual needs of the patient. Government regulation does not prevent inadequate care, however. A range of quality, from excellent to poor, is found in agencies subject to extensive regulation, and inadequate care is given by regulated and unregulated providers and in regulated and unregulated settings (305,524,563,816,821, 836,875).

Many factors contribute to the persistence of poor-quality care despite government regulation. The factor cited most often is inadequate funding for services (87,205,331,376,392,563). A related factor is the shortage of qualified personnel—especially nurse's aides, home health aides, and homemakers who provide much of the paid personal care for people with dementia (109,305,331,563,821,852). The shortage of qualified aides and homemakers is due in large part to inadequate funding. These individuals are paid very little. They are often poorly trained. Turnover is high, and those who receive training do not necessarily stay with the job. It is said that nursing homes and home care agencies compete for workers with McDonalds and other fast food restaurants—and often lose (747).

A third factor that is cited as contributing to the persistence of poor-quality care despite government regulation is deficiencies in regulatory procedures (17,305,392,563,814,821,831,852). Deficiencies in regulatory procedures include the use of inappropriate standards for evaluating quality, infrequent monitoring of care, and lack of credible sanctions for poor care. Many regulatory programs are underfunded and do not have sufficient staff for inspections and enforcement proceedings. This weakens the regulatory effort.

Government and nongovernment agencies and voluntary associations are working to improve regulatory procedures. A description of their efforts and analysis of the potential for their success would require another full study. Suffice it to say that efforts to improve regulatory procedures for nursing homes and board and care facilities have been under way for more than 10 years, with some but certainly not full success. Efforts to improve regulatory procedures for in-home services are only beginning. Many people will have to select services long before government regulatory programs are improved sufficiently to guarantee that all available services are at least of adequate quality.

In the meantime, the question posed here is whether the results of existing regulatory procedures would be helpful to people who are trying to select good services. If a provider has a State license, can families assume the provider will give good care? If a nursing home is certified by Medicare, does that mean it provides good care? Is there information from government inspections of nursing homes and home health care agencies that is available to families and is or could be valuable to them in selecting services?

The answers to these questions vary from one State and locality to another, for different types of providers, and for services paid for by different funding sources. Much of the information needed to answer the questions is not available. It is probably correct to conclude, however, that the results of existing regulatory procedures could be useful to some people who are trying to select services, with the following important qualifications:

- *Not all services that might be needed for people with dementia are regulated.* Although all States regulate some types of board and care facilities, they do not regulate other types. Adult day centers are not regulated in some States. Home health care agencies must be certified by Medicare and Medicaid in order to receive reimbursement from those funding sources, but many agencies that provide in-home services are not eligible for or do not seek Medicare or Medicaid certification. Many States license agencies that provide some kinds of in-home services, but agencies that provide other kinds of in-home services are not required to be licensed, and some States do not license any home care agencies (305,821,852). Moreover, individual in-home workers employed by home care agencies differ in their abilities and motivation; the agency's license, if any, does not reflect these differences. Lastly, individual in-home workers who are not employed by an agency and are hired from a newspaper ad or other such source are not regulated in most States.
- *Information from licensing, certification, and PRO review procedures may be difficult for families and others to obtain.* In 1988, for the

first time, the U.S. Department of Health and Human Services released information from Medicare and Medicaid nursing home surveys. To get information about other types of agencies and service providers, one would have to know that the information exists; find out which State or local government office keeps the information; obtain permission to see it; and probably go there to do so. Some agencies require a prior written request for information and charge a fee. OTA does not know how many people attempt this process or succeed in getting the information they want.

- *Regulatory procedures are often based on minimum standards and/or standards that are not directly related to people's primary concerns about quality.* State licensing requirements for professionals and service providers often set minimum standards for training and experience. Licensing requirements for some types of agencies focus only on fire and safety standards. The criteria used in some survey and certification procedures translate only indirectly into quality of care. Thus, the information about quality that families and others are looking for may not be contained in the findings of regulatory procedures.
- *People may have difficulty interpreting information from regulatory procedures.* Some regulatory procedures are lengthy and complex. Reports of their findings are not written for the layperson. Moreover, people who are not familiar with the procedures and the agencies being surveyed may not know which findings are noteworthy. In support of this observation, one OTA advisory panelist commented, "There are violations, and then there are violations!" (390).
- *Information from existing regulatory procedures is not dementia-specific.* OTA is not aware of any State or locality that regulates services for people with dementia using different criteria or procedures than it uses to regulate services for people with other diseases and conditions, although some States now are developing criteria to evaluate "special care units" in nursing homes. Since dementia-specific criteria have not been used in regulatory procedures (and generally have not been available), information about aspects of agencies' services that might make one agency's services more appropriate than another agency's services for a person with dementia may not be collected in the regulatory process or included in regulatory reports.
- *Information derived from regulatory procedures may not be correct.* Some regulatory procedures rely on notes in patients' medical records and the agency's written policies to evaluate quality of care rather than on direct observations of the process of care. This approach can lead to what is called "paper compliance"—i.e., agencies meet quality standards on the basis of documentation in patients' medical records and written policies rather than actual care they provide (385,925). Even when inspectors do observe the process of care, what they see may not be the ordinary process of care, but rather a special show put on to impress them (120).

All these factors limit the usefulness of findings from government regulatory procedures for families who are trying to select good services.

It is not clear to what extent individuals and agencies that refer people to services use the findings from government regulatory procedures as indicators of the quality of services. OTA informally asked about 20 individuals and agencies that make referrals for people with dementia: 1) whether they check to see that service providers to whom they refer patients have required licenses or certification, and 2) whether they review government inspection reports on agencies to which they refer patients. The majority answered "no" to both questions. State long-term care ombudsmen do often use reports of nursing home inspections in their discussions with people who are trying to select a good nursing home.

Government regulatory programs could be designed to produce information about quality that would be helpful for people who are trying to select good services (385,738), but existing programs are not designed for this purpose. The Omnibus Budget Reconciliation Act of 1987 mandated changes in many requirements for Medicare and Medicaid certification of nursing homes and home health care agencies, including a new survey protocol for home health care agencies and changes in nursing home regulations that also will result in issuance of a new survey protocol. These new protocols should be designed so that the information they collect is useful to families and others who are trying to select good services and the resulting information should be presented in a format and written in language that a layperson can understand.

Voluntary Accreditation Programs

Some agencies that provide services for people with dementia voluntarily comply with requirements of independent associations, such as the Joint Commission on Accreditation of Health care Organizations (JCAHO), the National League for Nursing (NLN), and the National Home Caring Council of the Foundation for Hospice and Home Care (FHHC). JCAHO accredits hospitals, nursing homes, hospital-affiliated home health care agencies, and beginning in 1988, other home health care agencies. Most hospitals in the United States are JCAHO-accredited, as are more than half of all hospital-affiliated home health care agencies (628) and a small proportion of nursing homes (about 1,400 in 1986) (563).

NLN, in conjunction with the American Public Health Association, accredits home health care agencies. FHHC, a sister organization of the National Association for Home Care, accredits homemaker-home health aide agencies. Very few agencies are accredited by either group: as of 1986, about 100 agencies had NLN accreditation, and about 140 had FHHC accreditation (734).

Agencies that seek JCAHO, NLN, or FHHC accreditation choose to be evaluated and pay for the survey process that leads to accreditation. One might assume, therefore, that it is important to these agencies to provide high-quality care and to be recognized for doing so. If that is true, accreditation might be a useful indicator of quality for people who are trying to locate good services.

There have been very few attempts to compare the quality of care provided by accredited and nonaccredited agencies, however (832). In addition, although the outcome of an accreditation survey is public information, the full report of an evaluation usually is not, so one cannot review findings of the survey with respect to specific standards.

Families and others who are trying to select good services probably are not aware of accreditation. Most books and pamphlets that advise people about locating services for people with dementia do not mention it. Moreover, when OTA informally asked individuals and agencies that make referrals for people with dementia whether they refer people to home care agencies that are not accredited by JCAHO, NLN, or FHHC, most were unsure, and several acknowledged that they did not know very much about accreditation for home care agencies.

Internal Quality Assurance Programs

Many health care, social service, and other agencies have an internal process to monitor quality of care and correct problems that are found. Internal quality assurance is widely advocated as a way for agencies to maintain acceptable quality of care. Internal quality assurance safeguards quality if monitoring is done systematically by people who have the authority and resources to correct problems (732). Otherwise, quality assurance can deteriorate into a formality that diverts staff from patient care and other important functions.

Although agencies with an effective internal quality assurance program may provide better care than other agencies, families and other outsiders cannot know whether a particular agency's quality assurance program is effective or just a formality. For them, knowing whether an agency has an internal quality assurance program is not a useful indicator of quality.

Other Possible Sources of Information

In some localities, private agencies and voluntary associations collect and publicize information about service providers. In New York City, for example, the United Hospital Fund makes annual nursing home inspections and then publishes information obtained from the inspections (561).

Newspapers and other publications sometimes rate agencies and health care professionals based on the opinions of consumers or other health care professionals. An example is the publication, *Washington Consumers' Checkbook*, which has published ratings of hospitals (885) and recently asked people to evaluate homemaker/home health care agencies they had used. Ratings in commercial publications are likely to appear as a feature item, on a one-time basis, and not to be updated regularly. According to the editor of *Washington Consumers' Checkbook*, the time required to conduct surveys and interpret the findings on a regular basis may not be justified from a business standpoint because these features do not attract many additional readers (428).

Changes in ownership, management, or key staff in nursing homes and other agencies can have a dramatic effect on quality of care. Such changes occur frequently in some agencies, so to be accurate, ratings must be updated. Private agencies and voluntary associations may not have the resources to update ratings regularly.

Many books and pamphlets that inform people about the types of health care, long-term care, social, legal, and other services that may be available also contain suggestions about how to evaluate services and lists of questions for families and others to ask service providers. Figure 5-2 is an example of a checklist of questions for families who are trying to select a nursing home.

Several national organizations have developed initiatives to help people become informed consumers of services for themselves or volunteer advocates to help others select good services. The National Council on the Aging's project "Long-Term Care CHOICES," sponsored several community forums in Pennsylvania in 1987 to educate older people and their families about long-term care options. Similar forums were planned for other areas of the country (308). The CHOICES project produced a series of pamphlets about long-term care and a manual for organizing a consumer education campaign on long-term care.

The American Association of Retired Persons (AARP) sponsors many projects to educate people about long-term care and to train them to be informed consumers of long-term care services. One project in Washington, DC, is training volunteers to be "home care advocates" to help other people locate good home care services (791).

Summary

Many of the books and pamphlets that offer advice about obtaining services for people with dementia stress that the final decision about services rests with the demented person's family. These publications urge families to talk to people, ask questions, and visit agencies before choosing one, and they recommend many possible sources of information about the quality and appropriateness of services. OTA's review presented in the preceding section suggests that accurate information about quality and appropriateness is *sometimes* available from some of the recommended sources but is not *consistently* available from any of them. The most helpful information often comes from informal discussions rather than from formal referrals or reports. But many telephone calls may be necessary to find the right person to talk to.

Health care and social service professionals and some of the other possible sources of information may or may not be knowledgeable about the quality or appropriateness of available services. With a few exceptions (e.g., government regulatory programs and voluntary accreditation programs), none of the sources of information discussed above has a systematic method for evaluating quality. The validity of the information they provide, therefore, is difficult to judge.

Lastly, concerns about legal liability and organizational pressures may limit the ability of hospital discharge planners, some case managers, and others to make referrals based on considerations of quality. Families are unlikely to know that these individuals are subject to these legal and organizational constraints and may incorrectly assume that the referrals they receive are endorsements of the services.

Some people get helpful advice, but there are no sure sources of evaluative information, and many blind alleys. Sometimes, obtaining accurate information or a referral to a good service provider seems to be a matter of chance. Family caregivers who call a lot of agencies, talk to a lot of people, and ask a lot of questions probably increase the likelihood that they will find the information they need to select good services.

LIMITATIONS ON CAREGIVERS' ABILITY TO OBTAIN INFORMATION

The discussion in the preceding section suggests that obtaining accurate information about the quality and appropriateness of services for people with dementia is often difficult. Some families and other informal caregivers are able to obtain the information they need by contacting a variety of people and agencies, asking questions, and visiting potential service providers, but for a variety of reasons discussed in this section, other families and informal caregivers are not.

To obtain information about quality, caregivers first have to know which agencies or individuals, if any, provide the services they need. In many

Figure 5-2—List of Questions for Families Trying To Select a Nursing Home

Yes *No*

1. Does the home have a current license from the state? ____ ____
2. Does the administrator have a current license from the state? ____ ____
3. If you need and are eligible for financial assistance, is the home certified to participate in government or other programs that provide it? ____ ____
4. Does the home provide special services such as a specific diet or therapy that the patient needs? ____ ____

PHYSICAL CONSIDERATIONS

Yes *No*

5. Location
   a. Pleasing to the patients? ____ ____
   b. Convenient for patient's personal doctor? ____ ____
   c. Convenient for frequent visits? ____ ____
   d. Near a hospital? ____ ____
6. Accident prevention
   a. Well lighted inside? ____ ____
   b. Free of hazards underfoot? ____ ____
   c. Chairs sturdy and not easily tipped? ____ ____
   d. Warning signs posted around freshly waxed floors? ____ ____
   e. Handrails in hallways and grab bars in bathroom? ____ ____
7. Fire safety
   a. Meets federal and/or state codes? ____ ____
   b. Exits clearly marked and unobstructed? ____ ____
   c. Written emergency evacuation plan? ____ ____
   d. Frequent fire drills? ____ ____
   e. Exit doors not locked on the inside? ____ ____
   f. Stairways enclosed and doors to stairways kept closed? ____ ____
8. Bedrooms
   a. Open on to hall? ____ ____
   b. Window? ____ ____
   c. No more than four beds per room? ____ ____
   d. Easy access to each bed? ____ ____
   e. Drapery for each bed? ____ ____
   f. Nurse call bell by each bed? ____ ____
   g. Fresh drinking water at each bed? ____ ____
   h. At least one comfortable chair per patient? ____ ____
   i. Reading lights? ____ ____
   j. Clothes closet and drawers? ____ ____
   k. Room for a wheelchair to maneuver? ____ ____
   l. Care used in selecting roommates ____ ____
9. Cleanliness
   a. Generally clean, even though it may have a lived-in look? ____ ____
   b. Free of unpleasant odors? ____ ____
   c. Incontinent patients given prompt attention? ____ ____
10. Lobby
    a. Is the atmosphere welcoming? ____ ____
    b. If also a lounge, is it being used by residents? ____ ____
    c. Furniture attractive and comfortable? ____ ____
    d. Plants and flowers? ____ ____
    e. Certificates and licenses on display? ____ ____
11. Hallways
    a. Large enough for two wheelchairs to pass with ease? ____ ____
    b. Hand-grip railing on the sides? ____ ____
12. Dining room
    a. Attractive and inviting? ____ ____
    b. Comfortable chairs and tables? ____ ____
    c. Easy to move around in? ____ ____
    d. Tables convenient for those in wheelchairs? ____ ____
    e. Food tasty and attractively served? ____ ____
    f. Meals match posted menu? ____ ____
    g. Those needing help receiving it? ____ ____
13. Kitchen
    a. Food preparation, dishwashing, and garbage areas separated? ____ ____
    b. Food needing refrigeration not standing on counters? ____ ____
    c. Kitchen help observe sanitation rules? ____ ____
14. Activity rooms
    a. Rooms available for patients' activities? ____ ____
    b. Equipment (such as games, easels, yarn, kiln, etc.) available? ____ ____
    c. Residents using equipment? ____ ____
15. Special-purpose rooms
    a. Rooms set aside for physical examinations or therapy? ____ ____
    b. Rooms being used for stated purpose? ____ ____
16. Isolation room
    a. At least one bed and bathroom available for patients with contagious illness? ____ ____
17. Toilet facilities
    a. Convenient to bedrooms? ____ ____
    b. Easy for a wheelchair patient to use? ____ ____
    c. Sink? ____ ____
    d. Nurse call bell? ____ ____
    e. Hand grips on or near toilets? ____ ____
    f. Bathtubs and showers with nonslip surfaces? ____ ____
18. Grounds
    a. Residents can get fresh air? ____ ____
    b. Ramps to help handicapped? ____ ____

SERVICES

19. Medical
    a. Physician available in emergency? ____ ____
    b. Private physician allowed? ____ ____
    c. Regular medical attention assured? ____ ____
    d. Thorough physical immediately before or upon admission? ____ ____
    e. Medical records and plan of care kept? ____ ____
    f. Patient involved in developing plans for treatment? ____ ____
    g. Other medical services (dentists, optometrists, etc.) available regularly? ____ ____
    h. Freedom to purchase medicines outside home? ____ ____

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20. Hospitalization
    a. Arrangement with nearby hospital for transfer when necessary? ___ ___

21. Nursing services
    a. RN responsible for nursing staff in a skilled nursing home? ___ ___
    b. LPN on duty day and night in a skilled nursing home? ___ ___
    c. Trained nurse's aides and orderlies on duty in homes providing some nursing care? ___ ___

22. Rehabilitation
    a. Specialists in various therapies available when needed? ___ ___

23. Activities program
    a. Individual patient preferences observed? ___ ___
    b. Group and individual activities? ___ ___
    c. Residents encouraged but not forced to participate? ___ ___
    d. Outside trips for those who can go? ___ ___
    e. Volunteers from the community work with patients? ___ ___

24. Religious observances
    a. Arrangements made for patient to worship as he or she pleases? ___ ___
    b. Religious observances a matter of choice? ___ ___

25. Social services
    a. Social worker available to help residents and families? ___ ___

26. Food
    a. Dietitian plans menus for patients on special diets? ___ ___
    b. Variety from meal to meal? ___ ___
    c. Meals served at normal times? ___ ___
    d. Plenty of time for each meal? ___ ___
    e. Snacks? ___ ___
    f. Food delivered to patients' rooms? ___ ___
    g. Help with eating given when needed? ___ ___

27. Grooming
    a. Barbers and beauticians available for men and women? ___ ___

ATTITUDES AND ATMOSPHERE

28. General atmosphere friendly and supportive? ___ ___

29. Residents retain human rights?
    a. May participate in planning treatment? ___ ___
    b. Medical records are held confidential? ___ ___
    c. Can veto experimental research? ___ ___
    d. Have freedom and privacy to attend to personal needs? ___ ___
    e. Married couples may share room? ___ ___
    f. All have opportunities to socialize? ___ ___
    g. May manage own finances if capable or obtain accounting if not? ___ ___
    h. May decorate their own bedrooms? ___ ___
    i. May wear their own clothes? ___ ___
    j. May communicate with anyone without censorship? ___ ___
    k. Are not transferred or discharged arbitrarily? ___ ___

30. Administrator and staff available to discuss problems?
    a. Patients and relatives can discuss complaints without fear of reprisal? ___ ___
    b. Staff responds to calls quickly and courteously? ___ ___

31. Residents appear alert unless very ill? ___ ___

32. Visiting hours accommodate residents and relatives? ___ ___

33. Civil-rights regulations observed? ___ ___

34. Visitors and volunteers pleased with home? ___ ___

Scoring

Generally, the best home is the one for which you check the most "yes" answers. However, different homes offer different services. You must decide which services are most important to you.

If the answer to any of the first four questions is "no," do not use the home.

SOURCE: L.P. Gwyther, "Nursing-Home-Care Issues," *Understanding Alzheimer's Disease*, M.K. Aronson (ed.) (New York, NY: Charles Scribner & Sons, 1988).

communities, that information is difficult to obtain.[12] To understand why they should investigate different service providers, caregivers need to know that available services are likely to vary considerably in their quality and appropriateness for people with dementia; some caregivers do not know this (57).

In addition, it takes time to evaluate different service providers. Many caregivers delay looking for services until their situation has become desperate. Consequently, they are trying to locate services in an atmosphere of crisis in which there is no time to contact individuals and agencies that might be able to give advice about the quality and appropriateness of services (289,767).

Even if caregivers have time, some of them do not have anyone to care for their demented relative while they make telephone calls or visit agencies. Some caregivers lack transportation to visit agencies, and some are physically or cognitively impaired themselves. Furthermore, deciding to place a relative or friend in a nursing home is emotionally upsetting to many people (84,517,884), and decisions about other services may be upsetting as well. People who are upset may have difficulty remembering the questions they are supposed to ask providers and

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[12] For more information about the difficulty of obtaining information about the availability of services, see ch. 2.

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keeping track of what they have heard from various sources about the quality of different services.

Another important point is that some people in this country have never or rarely called a government agency or another source to ask for information or advice. Because of personality, socioeconomic status, educational or cultural background, and/or language differences, some individuals may find asking for information or advice very difficult.

Asking questions of service providers is also difficult for some people. Books and pamphlets for families of people with dementia and for elderly people often include lists of questions they are supposed to ask about agencies and service providers they may use. These lists are often long and all-inclusive. Some questions are for the family to answer, but most are for the service provider. Some families would be uncomfortable asking a service provider all or even a portion of the questions.

For all of these reasons, some families and other informal caregivers may be unable to obtain the information they need to make informed choices about services. A linking system that relied on families and other informal caregivers to function as informed consumers in selecting services for people with dementia would not meet the needs of families and other caregivers who cannot do so.

Finally, although the discussion here has focused solely on the limitations on caregivers' ability to obtain information about the quality and appropriateness of services, the reader should keep in mind that at least 10 percent of people with dementia have no informal caregiver to help them.[13] Clearly, those individuals are not able to obtain for themselves information about the quality and appropriateness of services. Nor would they be able to use the information, even if they could obtain it.

APPROACHES FOR DEVELOPING CRITERIA TO EVALUATE THE QUALITY OF SERVICES

The development of criteria to evaluate the quality and appropriateness of services for people with dementia is probably the most important step that could be taken to enable a federally mandated linking system to connect people with dementia to the best available services. Certainly if a linking system were going refer people to or arrange for them only services that met certain standards, the standards would have to be based on accepted criteria. As noted at the beginning of this chapter, it is not the function of a linking system to develop criteria to evaluate services, but this section discusses some of the criteria that might be used, who should develop them, and who could use them.

Criteria to evaluate the quality of services for people with dementia ultimately must be based on agreed-on goals and proven methods of care. Since there is not yet a consensus about the goals of care for people with dementia, and the effectiveness of many methods of care has not been tested, it is premature to establish comprehensive criteria to evaluate quality. Once set, the criteria could become entrenched and discourage the kind of experimentation that has led to innovative services and care methods in the past few years. This outcome would be especially likely if the criteria were adopted for government regulatory purposes.

In developing its ''Best Practices for Special Care Programs for People With Alzheimer's Disease and Related Disorders,'' the American Association of Homes for the Aging (AAHA) has been wary of this possibility. AAHA emphasizes that the ''best practices'' are not criteria to assess special care units but rather guidelines for nursing homes that may establish such a unit. They are intended to highlight desirable outcomes and examples of good care (793).

The tasks of specifying goals, identifying effective methods of care, and developing criteria to measure quality and effectiveness are interrelated. Conclusions in one area may clarify or resolve issues in other areas. As tentative goals are set, possible methods of achieving them can be identified and tested. At the same time, as methods of care are tested, it becomes clearer what goals are achievable. A major unresolved question with respect to long-term care services for people with dementia, for example, is the extent to which rehabilitation is possible. Is it reasonable to expect improvements in cognitive ability or functioning in this patient population? (390). The answer to that question, which must be derived from research and experimentation with alternate methods of care, will in turn determine what goals are realistic for services for people with dementia.

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[13] For the derivation of this estimate, see ch. 1.

Even though it is premature to establish comprehensive criteria to evaluate the quality of services for people with dementia because of the lack of agreed-on goals and proven methods of care, an attempt to identify possible criteria is helpful in pointing out areas of agreement and disagreement and areas in which further research would be useful. The following discussion is intended in that spirit.

What Criteria Might Be Used?

Two prerequisites for good care that are cited in virtually all books, pamphlets, and articles about services for people with dementia are that the service providers be knowledgeable about dementia and that they be skilled in caring for or responding to the special needs of people with dementia. OTA is not aware of any other factors that are so consistently cited as prerequisites for high-quality, appropriate services for people with dementia.

OTA's 1987 report *Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias* discussed the problems involved in attracting and retaining skilled, knowledgeable personnel to work with dementia patients and the education and training needs of professionals, paraprofessionals, and nonprofessionals who care for these patients (831). That report described education and training needs in terms of both factual information and relevant experience.

If there were criteria that accurately measured a service provider's knowledge about dementia and skills in working with people with dementia, those criteria probably also would be valid structural indicators of the quality and appropriateness of the services. In many fields, an individual's knowledge and skills are represented by his or her credentials (e.g., educational degrees, licenses, certificates) or job title. Although some aspects of the knowledge and skills of many professional, paraprofessional, and nonprofessional groups are relevant to the care of people with dementia, OTA is not aware of any group with a uniform credential or job title, in which all or even most of the group members are knowledgeable about dementia and skilled in caring for people with dementia. Some physicians, nurses, social workers, lawyers, and psychologists are knowledgeable about dementia, whereas others are not. The same is true for nursing home aides, home health aides, homemakers, and other paraprofessional and nonprofessional service providers. Thus, neither credentials nor job title are valid criteria to measure service providers' knowledge about dementia and skills in working with people with dementia.

An alternate structural criterion is training. Dementia-related training often encompasses the nature and course of diseases that cause dementia, symptoms, patient care needs, recommended responses to common behavioral problems, and methods for supporting family caregivers. Many public and private agencies and voluntary associations offer training for all kinds of people who work with dementia patients. Training manuals have been developed by Alzheimer's Association chapters, provider associations, and others.[14]

Some Alzheimer's Association chapters have or are developing procedures for formally certifying people they have trained (183). At least one chapter certifies in-home respite and personal care workers it has trained. When someone contacts the chapter for information about such workers, he or she is given the names of people the chapter has certified. The director of the Cleveland Alzheimer's Association Chapter points out that chapters also could certify agencies if they have trained the agency's staff. Because of high staff turnover in some nursing homes and home care agencies, however, certification would lose its meaning quickly unless training were repeated frequently (183).

To choose training of service providers as a structural criterion to measure the quality and appropriateness of services assumes that training about dementia and how to care for people with dementia significantly increases the trainee's knowledge and skills in working with people with dementia—an assumption that is widely held but has not been proven in this or related contexts (31,904). The content and duration of the training, who provides it, whether trainees are tested in any way, and whether the training is reinforced over time probably influence its effectiveness. Although some members of the advisory panel for this OTA study considered training a useful structural indicator of quality and appropriateness, others considered it a weak, unproven intervention that generally is not a valid indicator of quality.

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[14] See, for example: E.L. Ballard and L.P. Gwyther, *In-Home Respite Care: Guidelines for Training Respite Workers Serving Memory-Impaired Adults* (50); C.J. French et al., *Understanding and Caring for the Person With Alzheimer's Disease* (231); L.P. Gwyther, *Care of Alzheimer's Patients: A Manual for Nursing Home Staff* (285); J.T. Harkulich and B.A. Calamita, *A Manual for Caregivers of Alzheimer's Disease Clients in Long-Term Care* (618); and R. Kahn et al., *How To Care for the Alzheimer's Disease Patient: A Comprehensive Training Manual for Homemaker-Home Health Aides* (378).

Some members of the OTA advisory panel pointed out that it is often easier to obtain agreement about indicators of poor quality than of good quality. They suggested that identifying negative outcomes (e.g., patient agitation and screaming) and clearly undesirable structural and procedural indicators (e.g., lack of staff training and inappropriate use of psychotropic medications to control patient behavior) might make available some information about quality without setting comprehensive criteria. Certainly information about the performance of different service providers with respect to these negative criteria would help families and others to avoid very poor-quality care.

Many other criteria for evaluating the quality and appropriateness of services for people with dementia have also been proposed. Some researchers who are conducting a 3-year study that compares nursing homes with "special care units" and nursing homes without such units hope that their findings will allow them to derive indicators of quality (761). Outcome criteria they are considering include:

- measures of acute health care service utilization, such as hospitalization rates and emergency room rates;
- measures of mortality and morbidity, including death, fractures, development of decubiti (bed sores), and medication reactions;
- changes in functional status, including development of contractures, loss of ability to ambulate, and changes in self-care status, socialization, or mental status;
- changes in the number and intensity of behavioral disturbances; and
- changes in overall health (761).

Structural and process criteria they are considering include:

- staff-to-patient ratios;
- staff training;
- facility design;
- environmental characteristics (e.g., noise, lighting, personal items in the patient's room);
- use of medications;
- patient involvement in activities;
- involvement of families; and
- staff morale (761).

Caregiver burden is another outcome criterion that seems particularly relevant for certain services for people with dementia. On the other hand, many factors other than the quality and appropriateness of services affect caregiver burden. Outcomes are valid indicators of quality only if they are attributable to the process of care. In practice, therefore, a measure of caregiver burden may not be a valid indicator of quality.

Patient satisfaction and caregiver satisfaction with services are other outcome criteria that might be used to assess quality and appropriateness. Although people who have used a service may be a valuable source of information for others who are trying to select good services, OTA is not aware of any organization that routinely collects people's opinions about services they have used for individuals with dementia, analyzes and summarizes the findings, and makes them available to other people. OTA is also not aware of any research on the reliability or validity of patient and/or caregiver satisfaction as indicators of the quality of services for people with dementia.

Research on patient satisfaction as an indicator of the quality of ambulatory and inpatient medical care was reviewed for OTA's 1988 report *The Quality of Medical Care: Information for Consumers* (832). Over 450 relevant publications were screened, and 50 studies were analyzed in depth. The review indicated that:

- patients' ratings of the technical quality of care they received are somewhat inflated but generally in agreement with physicians' ratings of the same care;
- patients' ratings of the interpersonal aspects of care they received are generally in agreement with ratings by trained observers and others;
- patients are generally willing to discuss and rate their medical care;
- older people tend to rate the quality of their care more favorably than younger people, although the reason why is not known; and

- people tend to agree with attitude statements regardless of their content; thus favorably worded statements tend to elicit favorable comments, and negatively worded statements elicit negative comments—and this effect is particularly likely to occur among people of low socioeconomic status (832).

It is sometimes argued that patients' ratings of medical care reflect patients' attitudes about life in general. OTA's literature review suggests that the effect of patients' attitudes about life in general on their ratings of medical care, if an effect exists at all, is weak in the case of ratings of ambulatory and inpatient medical care (832).

Many people with dementia cannot evaluate the services they receive, but their families or other informal caregivers can. Some services are intended primarily to support family caregivers; obtaining caregivers' evaluations of those services, therefore, is clearly appropriate. In some instances, however, a family's evaluation of a service provided for the patient may differ from the evaluation the patient might make if he or she were capable of evaluating the service. For example, families sometimes consider certain activities provided in nursing homes or adult day care centers to be demeaning to their relative with dementia, even though the patient seems to like the activities and the staff believes they are beneficial. In such instances, the family's satisfaction with the services may not be a valid criterion to measure its quality or appropriateness for the patient (764).

Other factors also may affect the validity of patient and caregiver satisfaction as indicators of quality and appropriateness. Patients and families often are afraid to report poor-quality care because they fear retaliation against the patient or loss of the services (33,392). The validity of people's opinions about services also may be affected by the timing of the evaluation in relation to their use of the service (764), sociodemographic characteristics, their expectations for the service, and whether they paid for it. Anecdotal evidence suggests that some people who receive publicly funded services do not report poor-quality care because they think they do not deserve the services and that they should just accept whatever services they get (747)

It could be argued that since patients' and caregivers' opinions about services are, by definition, subjective, they cannot be valid indicators of quality. If an agency or voluntary association routinely asked patients and caregivers about the quality of services they have used, however, and a large number of responses were collected, idiosyncratic factors that might invalidate one individual's response would become less significant, and common observations and evaluations would emerge. It is these common findings that would be valuable to other people that are trying to select good services.

People's opinions are a particularly appropriate indicator of the quality of services if quality of life is a goal of such services. Other, more objective and more easily quantifiable criteria that frequently are used in regulatory programs and may be more acceptable to service providers do not necessarily reflect the values and preferences of patients and families (877).

Using patient and caregiver satisfaction as indicators of the quality of services for people with dementia has two other advantages, as well. These indicators could be used immediately, even before there is agreement about other criteria to assess quality. In addition, using them would make available some information about quality without setting other criteria that could discourage experimentation with alternate methods of care.

Who Should Develop the Criteria and Who Could Use Them?

Government agencies, private agencies, and voluntary associations each have a role in establishing criteria to evaluate the quality of services for people with dementia. Ultimately, Federal, State, and local government agencies determine what criteria are used in regulatory programs. Government agencies are unlikely to begin developing criteria to evaluate the quality of services for people with dementia, however, until they are required to do so for a dementia-specific program—e.g., a program that pays more for nursing home care in a special care unit than in other nursing home units. If regulations for nursing homes and home health care agencies are any example, it could take a long time for government agencies to develop criteria, and the results might not meet the needs of families and others who are trying to select good services.

The initial steps of setting goals and proposing and evaluating criteria to measure quality might be better accomplished by private agencies and voluntary associations than by government agencies. The tasks of soliciting, summarizing, and disseminating people's opinions about the quality of services they have used would probably be best accomplished by voluntary associations such as Alzheimer's Association chapters, some of which already perform some of the tasks informally. The most appropriate role for government with respect to developing criteria to evaluate the quality of services for people with dementia might be to fund research to evaluate and compare the effectiveness of alternate methods of care and to sponsor forums for discussion among health care and social service professionals, service providers, families, and others about goals and methods of care and criteria for evaluating quality.

Families and other informal caregivers could use any criteria that were developed and/or any available information about people's opinions about the quality of services to identify service providers who offer high-quality care. Other agencies and organizations could also use the criteria and any available information about people's opinions about the quality of services to evaluate service providers, with the result that information about the quality and appropriateness of services for people with dementia would be available from those sources.

An important, unresolved question is whether case managers and other employees of agencies that constituted a federally mandated linking system could use either the criteria or information about people's opinions about the quality of services to select the best available services for their clients or whether their use of such criteria and information would expose them, their agencies, or the linking system to unacceptable legal risks. To resolve this question will require a thorough analysis of the legal issues raised when an agency or system that links people to services provides its clients with information about the relative quality of available services or selects services for its clients on the basis of information about the quality and appropriateness of the services. The legal risks to the linking system and its employees are likely to be lessened to the extent that any information about quality and appropriateness given out by the linking system is perceived as accurate by service providers and others and to the extent that criteria used by case managers and other employees of the system to select services are seen to reflect the best available information from research and provider experience about what is good care for people with dementia.

Thus far, this chapter has focused primarily on how families and other informal caregivers can select good services and has ignored the problem of people with dementia who have no informal caregiver to help them. Certainly, as noted earlier, the information about quality and appropriateness that families and other informal caregivers need to make informed decisions about services should also guide decisions about services for people with dementia who have no informal caregiver. That can only happen if someone uses the information about quality and appropriateness to select services for these individuals. For that reason, it is particularly important that concerns about legal risks to a linking system and its employees for selecting services for its clients on the basis of information about the quality and appropriateness of the services be resolved expeditiously.

AGENCY PROCEDURES FOR MONITORING & CONTROLLING THE QUALITY OF SERVICES

Some agencies that link people to services have procedures for monitoring and controlling the quality of the services they arrange for their clients. Certain of these agencies provide services and therefore can assure (i.e., assess and correct problems in) the quality of those services directly. Other agencies contract for services; these agencies cannot assure the quality of services provided by any particular agency or individual, but they can use their contracting procedures to select service providers that meet certain standards. The capacity of these types of agencies to control the quality of services to which they link people is an important factor for policymakers to consider in deciding what type of agencies should constitute a system to link people with dementia to services.

This section describes some agencies' procedures for monitoring and controlling the quality of services, including procedures in which patients and families are involved in monitoring and controlling the quality and appropriateness of the services they receive. The potential role of case managers in monitoring and controlling the quality and appropriateness of services for their clients is discussed at the end of the section.

On Lok Senior Health Services, a San Francisco-based service delivery system, is an example of an agency that provides most services directly and has an internal quality assurance process to monitor and control quality (940).[15] Clients or their families make the decision to receive services from On Lok, but once that choice is made, On Lok assumes responsibility for quality of care.

Pennsylvania's Long-Term Care Assessment and Management Program (LAMP) is an example of a program that contracts with community agencies to provide services for its clients and has procedures for monitoring and controlling the quality of those services (652).[16] LAMP's clients are elderly people who are eligible for Medicaid-funded nursing home care but choose to remain at home. The State of Pennsylvania designates local agencies (primarily AAAs) as LAMP sites to provide a comprehensive assessment, develop of a plan of care, and arrange and monitor services for each client. In turn, the LAMP sites contract with community agencies to provide services.

Contracts between LAMP sites and community agencies that provide services for LAMP clients include many provisions related to quality (872). For example, the fiscal year 1987 contract between the Allegheny County LAMP site and the Visiting Nurse Association (VNA) of Allegheny County specifies services the VNA must provide; that the VNA must be able to respond to emergency requests within 24 hours; and that the VNA must have certain staff, an orientation program, a method for certifying employee participation in continuing education, and an internal quality assurance program. Staff must be licensed or certified as appropriate, and the agency must be certified by Medicare and Medicaid and accredited or eligible to be accredited by JCAHO, NLN, or the FHHC.

Ohio's Pre-Admission Screening System Providing Options and Resources Today (PASSPORT) program is like LAMP in that it provides case management and a package of services for people who are eligible for nursing home care but choose to remain at home (622).[17] The agencies that administer PASSPORT at the local level contract with other agencies to provide services for PASSPORT clients. Their contracts include numerous provisions to ensure the quality of services, including standards developed for many different kinds of service providers (32,623). The PASSPORT program's standards for homemaker services are shown in figure 5-3.

Illinois' Community Care Program (CCP) funds homemaker, chore, and adult day services for about 25,000 elderly clients through contracts with more than 200 community agencies, called vendors (51).[18] Clients may select a service provider, but it must be one of the vendors. The State of Illinois evaluates the performance of each vendor annually, using a 90-item review instrument that encompasses many aspects of quality and appropriateness. Vendors found to provide inadequate services are terminated from the program.

LAMP, PASSPORT, and CCP are State programs that go far beyond their State's licensing requirements, if any, and any relevant Medicare and Medicaid conditions of participation in their requirements for contractors. People who receive publicly funded services through different programs in the same States may not receive the same quality of care as clients of these programs.

New Jersey has taken a different approach. New Jersey's Medicaid agency requires community agencies that provide personal care or homemaker services to be accredited in order to be reimbursed for services to Medicaid patients. Since 1986, the Commission on Accreditation for Home Care, an organization that is independent of the State has accredited these agencies, based on uniform standards and an on-site inspection (168). As of August 1988, 45 agencies had applied for accreditation: 24 of these received accreditation; six were denied accreditation (primarily because of poor documentation, lack of evidence of appropriate supervision, or inadequate staffing); 10 were deferred and may reapply; and five withdrew their applications (430). New Jersey accepts accreditation by the Foundation for Hospice and Home Care (FHHC) in lieu of accreditation by the Commission, and 9 agencies have been accredited in that way.

In Tulsa, Oklahoma, five local sources of funding for home health aide, homemaker, companion, and chore services have pooled their funds and estab-

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[15] For more information about On Lok, see ch. 8.

[16] For more information about Pennsylvania's LAMP program, see ch. 7.

[17] For more information about Ohio's PASSPORT program, see ch. 7.

[18] For more information about Illinois' Community Care Program (CCP), see ch. 7.

Figure 5-3—The Ohio PASSPORT Program's Standards for Homemaker Services

Homemaker Services Standards

I. Homemaking services are provided by a homemaker who has met the education and training requirements for the PASSPORT program.

II. The homemaker provides timely services, maintains a safe and clean environment and is sensitive to the client and family's needs.

III. The homemaker performs tasks and duties according to the service care plan. The homemaker prioritizes and organizes tasks to achieve goals outlined on the care plan.

IV. The homemaker understands that client information is privileged knowledge. The homemaker holds all information in confidence.

V. Homemaking tasks assigned are performed under the supervision of the homemaker supervisor. The homemaker demonstrates knowledge and skills to perform assigned tasks.

VI. The homemaker recognizes changes in client conditions and behavior and reports and records according to PASSPORT and agency procedures.

VII. The homemaker participates as a health care team member and is responsible for communicating with other professional disciplines as appropriate.

SOURCE: R. Applebaum, S.J. Atchley, R. McGinnis, et al., *A Guide To Ensuring the Quality of In-Home Care: Final Report of Ohio's Quality Assurance Project* (Oxford, OH: Miami University, 1988).

lished a joint process to contract for these services.[19] The five funding agencies have formal procedures for monitoring the quality of the services provided by the contractor. Those procedures include sending questionnaires to local hospitals, clinics, and other referral sources to determine their satisfaction with the contractor's services. Client satisfaction with the contractor's services is also assessed by using a standard list of questions (see figure 5-4). This list of questions is used to interview about 10 percent of the agencies' clients annually (556).

In 1987, Senior Care Network, a private hospital-based case management agency in Pasadena, California, began a comprehensive program to monitor and control the quality of services to which it refers clients (795). Senior Care Network combines four case management programs: two of the programs contract with service providers, and two do not, but all four participate in the quality assurance program. Quality is monitored through quarterly meetings between the service providers and program staff; annual reevaluations; monthly client home visits by case managers; visits by program staff to the provider agencies; and vendor incident reports that often concern "no-shows" or late arrival by home makers and nurse's aides. If service providers accumulate a record of more than 5 percent "no-shows," case managers stop using that provider until the problem is corrected.

These models of service delivery, in which the quality of services is monitored and controlled by the agencies that provide, pay for, and/or arrange the

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[19] The Tulsa Long-Term Care Management Authority, an outgrowth of the five-agency effort described here, is discussed in ch. 7.

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Figure 5-4—Questions Used To Evaluate Client Satisfaction in Tulsa, Oklahoma

Client Satisfaction Questionnaire

Read each statement below. Circle the response that is most true. There are no right or wrong answers. No one from (home care agency) will see your responses. Your responses will not affect your services. If you wish, the interviewer will read the statements aloud.

1. I am comfortable with my worker from (home care agency) and I look forward to him or her coming to my house.
NEVER SOMETIMES USUALLY ALWAYS

2. If I have a problem or question about services I would be comfortable talking about it with my worker.
NEVER SOMETIMES USUALLY ALWAYS

3. If I had a problem I could not solve with my worker, I would be comfortable going to the supervisor.
NEVER SOMETIMES USUALLY ALWAYS

4. My worker knows what to do and does it with little or no supervision from me.
NEVER SOMETIMES USUALLY ALWAYS

5. The worker provides the services I expect.
NEVER SOMETIMES USUALLY ALWAYS

6. The worker finishes the job he/she is supposed to do.
NEVER SOMETIMES USUALLY ALWAYS

7. The worker takes longer than necessary to do the job.
NEVER SOMETIMES USUALLY ALWAYS

8. I can depend on my worker to arrive on time.
NEVER SOMETIMES USUALLY ALWAYS

9. The worker does not perform tasks I can do myself.
NEVER SOMETIMES USUALLY ALWAYS

10. I help decide what services I receive in my home.
NEVER SOMETIMES USUALLY ALWAYS

11. I am notified in advance if my worker will be late or cannot come.
NEVER SOMETIMES USUALLY ALWAYS

SOURCE: N.L. Mumma, "Quality and Cost Control of Home Care Services Through Coordinated Funding," *Quality Review Bulletin* 13(8):271-278, 1987.

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services, have considerable appeal, given the problems people face in obtaining accurate information about the quality and appropriateness of services otherwise. These models appear to respond to concerns raised in this chapter about families and other informal caregivers who are not able to obtain information about the quality and appropriateness of services themselves and people with dementia who have no informal caregiver to select services for them.

None of the programs described here is dementia-specific. The Medicare Alzheimer's Disease Demonstration that is being implemented at eight sites nationally requires each site to offer clients with Alzheimer's disease a range of in-home and community services (504). The sites are not required to contract for services, but that is an option. OTA does not know whether any of the sites have developed methods for monitoring and controlling the quality of contracted services or what methods of quality assessment and assurance will be used for brokered services.

Procedures for Involving Patients and Families in Monitoring and Controlling the Quality of Services

Giving patients and families greater control over the services they use is an approach that some agencies use to address concerns about the quality and appropriateness of services. This approach can be implemented through a variety of mechanisms, some of which have been discussed earlier:

- involving patients and families in developing the plan of care;
- having patients and families monitor services they receive;
- using patient and family satisfaction as indicators of quality;
- providing an effective grievance mechanism by which complaints from patients and families are received and acted on;
- giving patients and/or families control over the funds to pay for services; and
- involving patients and families in the overall design and evaluation of programs that provide services for them (735,919).

With the exception of patient and family monitoring of services, each of these mechanisms provides a way for patient and family values and preferences to influence the services they receive. In the case of people with dementia, it is probably more often the family than the patient who is actively involved in planning and evaluating services. As discussed earlier, the family can be seen either as representing the values and preferences of the patient in this context and/or as representing its own values and preferences.

Patient monitoring of services has been implemented formally in Ohio's PASSPORT program. Once a client's plan of care is developed, the client is given a checklist that indicates what services are to be provided and tells the client to call the case manager if specific problems arise (see figure 5-5). Whether planned services are actually received—i.e., whether a home health aide or homemaker shows up and does what he or she is supposed to do—is clearly a component of quality. Formal reporting mechanisms like Ohio's checklist offer a promising approach for monitoring it.

Many families informally monitor the quality of services provided for elderly relatives at home or in a nursing home (84,209,928). OTA is not aware of any research on the validity of families' reports about receipt or nonreceipt of services. OTA's literature review on patient satisfaction as an indicator of quality found that patients' reports about what medical services they receive are highly accurate (832).

Having patients and families report on receipt of services transfers only a small amount of control to them. Another approach that has rarely been implemented in publicly funded programs for elderly people but effectively transfers much more control to them, is giving them funds or vouchers to purchase services.

Family Survival Project, a San Francisco-based agency for brain-impaired adults, has implemented this approach in a program that gives family caregivers vouchers to purchase home care services.[20] The family is regarded as the employer of the service provider. This approach allows families to select home care workers who are acceptable to them, and Family Survival Project has encountered few problems with it (403).

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[20] For more information about Family Survival Project, see ch. 8.

Figure 5-5—Checklist Given to Clients in Ohio's PASSPORT Program

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Client: ______________________ Date: ____________________
Case manager: ________________ Telephone: ________________
Instructions: ____

Personal Care

___Bath
___Oral care
___Shampoo
___Shave
___Skin care
___Foot/nail care
___Dress

Mobility

___Transfers
___Walking
___Exercise
___Assistive device

Elimination

___Client to toilet
___Client to commode
___Client to bedpan
___Incontinent care
___Ostomy care
___Empty commode

Nutrition

___Meal planning
___Breakfast
___Lunch
___Dinner
___Snack
___Feed client
___Home delivered meals

Homemaking Tasks

___Kitchen cleaning
___Bathroom cleaning
___Living room cleaning
___Bedroom cleaning
___Change bed linens
___Grocery shopping
___Errands
___Trash removal
___Accompany to doctors

PLEASE CALL CASE MANAGER IF:

- **WORKER FAILS TO SHOW UP**
- **WORKER FAILS TO PERFORM DUTIES**
- **THEFT OR ABUSIVE CARE**
- **YOU WILL NOT BE HOME FOR SERVICE**

****SIGN SERVICE AUTHORIZATION FORM ONLY FOR THE EXACT HOURS WORKED.**

SOURCE: R. Applebaum, S.J. Atchley, R. McGinnis, et al., *A Guide To Ensuring the Quality of In-Home Care: Final Report of Ohio's Quality Assurance Project* (Oxford, OH: Miami University, 1988).

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In 1983 and 1984, the same approach was used in a Wisconsin demonstration project known as the "Consumer-Directed Services Initiative" (CDS) (919). Wisconsin's CDS provided participants or their families with vouchers to purchase services. The 70 participants included individuals of all ages with chronic disabilities who were eligible for nursing home care. Several of them were Alzheimer's patients. Participants had a service coordinator whose role was to ensure consumer direction:

> Unlike the traditional case manager who is accountable to a service-providing agency, the service coordinator . . . is directly responsible to the consumer. It is the consumer who decides what services are needed and how they should be provided. The service coordinator uses his or her knowledge of the service system and of the rights and entitlements of the disabled consumer to explore options which the consumer can choose among (919).

Wisconsin's CDS demonstration project concluded that giving people vouchers and the opportunity for choice was an empty gesture unless they were also given information about available service options, training in how to bargain with and influence providers, and support for doing so (919). The underlying assumption of the project was that the client was "the boss," with the power to hire and fire, and the provider was expected to carry out duties according to the client's preferences. Many clients and providers had difficulty with this employer/employee relationship. Expectations differed about what the provider would do; there were personality conflicts; and some providers found it difficult to respect the client's preferences about how he or she wanted services performed.

For most clients with Alzheimer's disease, Wisconsin's CDS demonstration project relied on the family to make decisions about services for the patient (919). The service coordinators who worked with these patients and families frequently had difficulty in deciding when, if ever, the values, preferences, and interests of the family should take precedence over the values, preferences, and interests of the patient and determining, in effect, "who is the client" (919).[21]

Case managers, health care and social service professionals, and others are sometimes ambivalent about giving patients or families control over services, partly because doing so challenges the concept that it is professionals that can and should evaluate client needs and prescribe appropriate treatment (311,737). On the other hand, some are justifiably concerned about the possibility that poor care will be provided or that the patient's needs will be neglected in such an arrangement. Family Survival Project monitors intermittently services purchased through the voucher program. In Wisconsin, the CDS service coordinator provided ongoing monitoring.

What Role Can Case Managers Play in Monitoring and Controlling Quality?

Many commentators have suggested that case managers or a case management agency could monitor and control the quality of services generally (48,175,230,386,737,877). In 1987, the Delegate Assembly of the American Bar Association passed a resolution on home care that said, in part:

> Experimentation with case management systems is widespread, but the current focus on case management centers largely on its potential to control costs. It may also offer tremendous potential as a tool for quality assurance and monitoring (19).

Case managers and case management systems do not automatically monitor and control quality. Case managers are employed by virtually all the agencies discussed in this report. Their functions vis-a-vis quality vary greatly, depending in large part on the organization, funding, sponsorship, and other characteristics of the agency that employs them. Case management agencies also differ in all these respects, and their current and potential ability to control quality of care also differs.

A recent review of the experiences of case managers in the $10 million National Long-Term Care Channeling Demonstration illustrates some of these differences (33).[22] The Channeling Demonstration, which was funded by the U.S. Department of Health and Human Services from 1980 to 1985, took place in 10 sites: in 5 sites, the case managers had funds to purchase services, and in 5 other sites they had only very limited funds. Case managers in both types of sites had difficulty monitoring the quality of homemaker and personal care services received by their clients. Some sites had contracts with homemaker/home health aide agencies, and at those sites, procedures for monitoring quality and responding to inadequate services were detailed in the contracts. At sites that did not have contracts with service providers, procedures for monitoring quality and responding to problems were less structured and less formal. Sites that had funds to purchase services used the threat of withholding payment to pressure providers into improving their services. That option was not available to sites that did not have funds to purchase services.

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[21] For further discussion of the issue of who is the client of an agency or program that links people with dementia to services, see ch. 4.

[22] The Channeling demonstration is discussed further in ch. 7.

These findings from the Channeling Demonstration and the discussion earlier in this chapter about case managers' role in providing families and others with information about the quality and appropriateness of services suggest that it is not case managers or case management per se that can monitor and control quality but rather case managers in an agency or service delivery system that has explicit procedures for this purpose. Policymakers should not assume, therefore, that simply involving case managers in a linking system will automatically guarantee that the linking system will monitor and control the quality of services.

CONCLUSION

Families and other informal caregivers need accurate information about the quality and appropriateness of services provided by different agencies and individuals. In the public debate about services for people with dementia, the need for better information about quality and appropriateness has been overshadowed thus far by concerns about insufficient availability of services. Anecdotal evidence indicates, however, that some patients and families who need services do not use them because they are afraid of poor-quality care. For them, availability of services is not the only concern.

Books, pamphlets, and articles about services for people with dementia suggest that caregivers are responsible for selecting good services and that information about quality and appropriateness—on which they could base their selection—is available from a variety of sources. OTA's review of those sources indicates that although the necessary information is sometimes available from many of the sources, it is not consistently available anywhere.

Moreover, referrals to service providers are sometimes misleading. Patients and families who are given the name of a service provider—particularly by a health care or social service professional, hospital discharge planner, or case manager—may assume that the referral is a recommendation based on that individual's knowledge of available service options. That assumption may or may not be correct.

To expect families who are severely stressed by the care of a relative with dementia to call many individuals to ask for information about quality; to locate, read, and understand facility inspection reports; or to correctly guess the basis on which a referral is made by a physician, discharge planner, case manager, or other individual is naive. To expect this of a person with dementia is even more so.

The chapter points out that the development of criteria to evaluate the quality and appropriateness of services for people with dementia is probably the most important step that could be taken to enable a federally mandated linking system to connect people with dementia to the best available services. It is not the function of the linking system to develop such criteria, however.

Developing comprehensive criteria to evaluate the quality and appropriateness of services for people with dementia will take the combined efforts of government agencies, private agencies, and voluntary associations. It will also take time. In the meantime, private agencies and voluntary associations could solicit caregivers' opinions about services they have used for a person with dementia and make that information available to other people who are trying to select good services. In addition, existing regulatory programs could be modified to collect and make available information that would be useful to people who are trying to select good services. Neither of these approaches would result in comprehensive criteria for evaluating the quality and appropriateness of services for people with dementia. These approaches would provide information that is not available now, however, and might lessen the problems families and others face in selecting services.

A federally mandated linking system could not select services for its clients on the basis of the quality and appropriateness of the services without criteria for evaluating quality and appropriateness, but the analysis in this chapter suggests that there are several types of information the system could provide caregivers of people with dementia to help them select good services. First, and most basic, the linking system could inform caregivers that there are differences in the quality and appropriateness of available services. Second, the system could inform caregivers about what, if any, information it will provide about the quality and appropriateness of services and about any factors that restrict the system and its employees from giving its clients accurate information about the quality and appropriateness of services or making referrals on the basis of quality. Third, the system could inform clients and their families about which service providers are licensed, certified, and/or accredited. Fourth, the system could give caregivers any available information about the quality of services, including, for example, information compiled by a voluntary association about families' and others' opinions about services they have used for a person with dementia. If Congress established a national system to link people with dementia to services, Congress could mandate that the linking system provide its clients with any or all of these types of information.

None of these types of information will solve the problem of how to ensure that people with dementia who are not capable of selecting services for themselves and have no relative or friend to help them are connected to the best available services. To solve that problem would require that the linking system select services for them on the basis of the quality and appropriateness of the services, which, as noted above, would require the development of criteria to evaluate quality and appropriateness. In the absence of the necessary criteria, Congress could mandate that the system refer clients only to licensed, certified, and/or accredited agencies and service providers; for reasons discussed earlier in this chapter, however, such a requirement would probably have only a very limited impact on the quality and appropriateness of the services these clients would receive. Congress could require that the linking system control the quality of services to which it refers clients by contracting with providers that meet certain specified standards, but the standards do not exist yet.

The chapter has discussed the need for a thorough analysis of the legal issues that are raised when an agency or system that links people to services provides its clients with information about the relative quality of available services or selects services for its clients on the basis of information about the quality and appropriateness of the services. If Congress established a national linking system for people with dementia, Congress could require the U.S. Department of Health and Human Services to conduct or contract for such an analysis. Congress could also immunize the linking system from legal liability for good faith efforts to disseminate information about the quality of services.

Finally, the chapter recognizes the insufficient availability of services in general, and the difficult problems that it creates for anyone trying to arrange good care. On the other hand, there are some good services in almost all communities and important gradations in quality among services that might be considered adequate. Making available information about quality supports the providers of good services and encourages others to improve, even within existing resource constraints.

Chapter 6

Linking Veterans With Dementia to VA and Non-VA Services

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Chapter 6

Linking Veterans With Dementia to VA and Non-VA Services

INTRODUCTION

The U.S. Department of Veterans Affairs (VA) operates the largest health care system in this country (509,837) and provides many of the kinds of services that may be needed for a person with dementia.[1] Only a small proportion of elderly American women are veterans, but, as of 1990, more than half of all American men over age 65 are veterans, and by the year 2000 that proportion will increase to two-thirds (854). The VA is a *potential* source of services for them. On the other hand, not all veterans with dementia are eligible for VA services, and the VA does not provide all of the kinds of services that may be needed for a person with dementia.

Some people believe that the VA should provide the full range of health care, long-term care, and other services that are needed for all veterans, including veterans with dementia. Others believe that the VA should provide at least all the health care services that are needed for all veterans. Still others believe that for financial and other reasons, the VA should not or cannot provide all needed services for all veterans; they believe that the VA should concentrate its resources on providing certain kinds of services—usually acute medical services—and that eligibility for VA services should be limited to certain types of veterans—usually veterans with service-connected disabilities and veterans with low income.[2]

The debate about what services the VA should provide and for whom is not the topic of this chapter. The chapter assumes that although the amount and kinds of services provided by the VA and the eligibility criteria for VA services will undoubtedly change from time to time, it is unlikely for a variety of reasons that the VA will ever provide all the services that may be required for all veterans with dementia. Therefore, many veterans with dementia will need to use non-VA services as well. The chapter focuses on problems in the process by which veterans with dementia are linked to VA services for which they are eligible and problems in the process by which they are linked to non-VA providers for services they cannot obtain from the VA.

Over the past few years, the Office of Technology Assessment (OTA) has heard complaints from some families and other informal caregivers of people with dementia about the difficulty of obtaining VA services for a veteran with dementia or even finding out what services are available from the VA for veterans with dementia. At the same time, OTA has heard from other families and informal caregivers about good services provided by the VA for individuals with dementia. Some of the caregivers who have reported that their relative or friend with dementia received good services from the VA say that they "just happened" to learn about the VA services and that they had not expected that the services they needed for the person with dementia would be available through the VA. Conversely, some families and others who have complained to OTA about the difficulty of obtaining VA services for an individual with dementia have reported that they did expect to receive the services they needed from the VA, and that they were disappointed and angry when those services were not available. OTA has also heard about families of people with dementia who have experienced long, frustrating waits during which they did not know whether the person with dementia would receive needed services from the VA.

People's diverse experiences in applying for and receiving VA services are illustrated in the results of a 1986 mail survey of families and other informal caregivers of people with dementia (926) commissioned by OTA for its previous assessment, *Losing a Million Minds: Confronting the Tragedy of Alzheimer's and Other Dementias*. Only a few of the 569 caregivers who responded to the 1986 survey reported that they had ever applied to the VA for services for their relative or friend with dementia. Of those that had applied, 45 percent said the person with dementia did not receive the needed services; in two-thirds of those cases, the main reason given was that the individual—although a veteran—did not have a service-connected disability. For the 55 percent that did receive VA services, 80 percent of the caregivers reported the services were good or excellent; 10 percent reported the services were average; and 10 percent reported the services were poor. One caregiver removed the veteran from the VA facility due to poor care. The survey did not ask the caregivers whether they had expected that the individual they were caring for would receive VA services or how they were linked to the VA services.

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[1] For a list of services that may be needed for a person with dementia, see table 1-2 in ch. 1.

[2] The eligibility criteria for VA health care and health-related services are discussed later in this chapter. Veterans with service-connected disabilities—i.e., disabilities that were incurred or aggravated during military service—have priority over other veterans in the receipt of VA services.

This chapter describes the VA health care and health-related services that may be helpful for an individual with dementia. In the course of this study, one OTA staff member visited several VA medical centers that are providing high-quality services of various kinds for veterans with dementia, and some of those services are described. The chapter discusses the reasons why some services that may be needed for an individual with dementia are not available from the VA and why some veterans with dementia are not eligible for VA services. It describes and analyzes existing problems in linking veterans with dementia to VA services for which they are eligible and to non-VA providers for services they need but cannot obtain from the VA.

Many of the problems discussed in this chapter have been addressed previously by the VA, the Senate and House Committees on Veterans' Affairs, and others, with respect to services for elderly veterans (641,820,854,855,859). In the early 1980s, for example, the VA and Harvard University collaborated in a project to develop options for increased coordination and sharing of VA and non-VA resources to improve access to appropriate care for older veterans (721). One product of that collaborative effort, a book entitled *Older Veterans: Linking VA and Community Resources*, raises many of the same problems discussed here with respect to linking veterans to VA and non-VA services (901a). Certain aspects of the service needs of people with dementia and the VA's eligibility requirements make these problems particularly difficult for veterans with dementia, however.

According to VA estimates, there are now about 400,000 veterans with dementia (76). Although the total number of veterans of all ages is decreasing, the number of older veterans is growing rapidly (854). Since the prevalence of dementia increases with age, the growth in the number of older veterans will result in an increase in the number of veterans with dementia. The VA estimates that there will be 50,000 new cases of dementia among veterans in 1990, and that the number of new cases of dementia among veterans will increase to 100,000 per year by the year 2000, before leveling off (76). By the year 2000, there will be 600,000 veterans with dementia (76). This large number of veterans with dementia is likely to create demands on the VA for a variety of services, and to increase the need for effective methods of linking veterans with dementia to VA and non-VA services.

If Congress mandated the establishment of a national system to link people with dementia to services, as discussed in this OTA report, the VA could take one of two possible roles in relation to the system. On the one hand, the VA could assume the sole responsibility for linking veterans with dementia to both VA and non-VA services. On the other hand, the responsibility for linking veterans with dementia to services could be split between the VA and the non-VA linking system; if this were done, the VA would retain the responsibility for linking veterans with dementia to VA services, and the non-VA linking system would assume primary responsibility for linking veterans with dementia to non-VA services. The pros and cons of these two options are discussed in chapter 1. This chapter provides information relevant to evaluating the two options.

VA HEALTH CARE AND HEALTH-RELATED SERVICES THAT MAY BE HELPFUL FOR VETERANS WITH DEMENTIA

The VA provides health care and health-related services through the Veterans Health Services and Research Administration (VHS&RA), previously called the Department of Medicine and Surgery. Administratively, the VHS&RA encompasses 7 Regions, 27 Districts, and 172 VA medical centers (676). Through the VHS&RA, the VA provides acute and extended (long-term) care services for veterans in VA hospitals, nursing homes, domiciliary care facilities, outpatient clinics, and in the veteran's home. Also through the VHS&RA, the VA pays for acute and extended-care services for veterans in non-VA hospitals, nursing homes, and board and care facilities and through non-VA physicians and other health care professionals. In fiscal year 1987, 1.4 million veterans were treated in VA hospitals, nursing homes, and domiciliary care facilities, and 19.8 million veterans were treated on an outpatient basis by VA staff (857). In that same year, the VA paid for the treatment of 94,000 veterans in non-VA hospitals, nursing homes, and board and care facilities and for 1.8 million outpatient visits to non-VA physicians and other health care professionals.

This section describes the health care and health-related services provided or paid for by the VA that may be helpful for veterans with dementia. In addition to providing and paying for health care and health-related services, the VA also provides education and training for health care professionals and pays for biomedical and health services research. Some of the VA's training and research initiatives that pertain to dementing diseases and the care of people with dementia are also described.

Not all the services described in the following sections can be obtained by all veterans with dementia for a variety of reasons discussed later in this chapter. These reasons include the eligibility criteria for the services and the lack of sufficient VA services in relation to the large number of veterans who need them. In addition, most VA health care and health-related services are furnished at the 172 VA medical centers. As a result, VA services are, in practice, more readily accessible by veterans who live near one of the medical centers than by other veterans. VA services that are only provided by certain VA medical centers are more readily accessible by veterans who live near those centers.

Acute Care Services

Acute medical care in the VA is provided by 172 VA hospitals, 235 VA outpatient clinics, and numerous non-VA hospitals and physicians (815,837). For veterans with dementia, inpatient and outpatient acute medical services are important for the management of acute illnesses and acute episodes of chronic illnesses, both of which can exacerbate the cognitive deficits caused by a dementing illness. Acute care facilities and services are also important for diagnosis and assessment. VA hospitals and outpatient clinics typically employ physicians with the medical specialties that may be needed to diagnose diseases that cause dementia. In addition, VA hospitals and outpatient clinics employ many other health care professionals, including nurses, psychologists, social workers, and other therapists, who frequently function as a multidisciplinary team and do or could provide comprehensive, multidisciplinary assessments for veterans with dementia.

Extended (Long-Term) Care Services

A variety of long-term care services, called "extended-care" services in the VA, are available at many VA medical centers. Most of these extended-care services are provided in institutional settings, such as nursing homes and domiciliary care facilities, but some are provided in noninstitutional settings. Both types of extended-care services are potentially helpful for some veterans with dementia.

Institutional Extended-Care Services

The VA provides or pays for institutional extended-care services that may be helpful for veterans with dementia through at least five programs. One of these programs provides *extended hospital care* in intermediate medical care beds—i.e., VA hospital beds that are used for veterans who require less than hospital and more than skilled nursing care. A second program, the *VA nursing home program*, provides skilled nursing care in VA nursing homes. In fiscal year 1989, this program served over 27,000 veterans in 118 VA nursing homes (837). The VA nursing homes had a total of 12,530 beds and an average daily census of 11,500.

A third program that provides institutional extended-care services for veterans is the *community nursing home program*, which permits each of the 172 medical centers to place veterans in non-VA nursing homes that provide either skilled or intermediate level care under contract with the VA. In fiscal year 1989, 3,675 community nursing homes cared for 32,000 veterans through this program (837). The average daily census was 9,305.

A fourth program that provides institutional extended-care services is the *domiciliary care program* that is intended for ambulatory veterans who need health-related services but do not require hospitalization or the skilled or intermediate level of care provided in the VA or community nursing home programs. In fiscal year 1989, 18,000 veterans received care in the VA's 29 domiciliary care facilities, which had an average daily census of 6,000 (837).

Finally, institutional extended-care services are provided by *State Veterans' Homes* that receive a per diem grant from the VA for the care of eligible veterans. State Veterans' Homes can also receive

VA grants to build or acquire new facilities; funding is available for up to 65 percent of construction costs. In fiscal year 1989, there were 55 State Veterans Homes in 36 States (837). These State Veterans Homes had a total of 19,000 beds, including nursing home and domiciliary care beds, as well as some hospital beds.

Noninstitutional Extended-Care Services

The VA provides or pays for three programs that offer noninstitutional extended-care services that may be helpful for some veterans with dementia: hospital-based home care, adult day health care, and community residential care. The *hospital-based home care program* provides in-home medical, nursing, rehabilitative, and other services for homebound veterans. A multidisciplinary team furnishes the services and manages the veterans' care. The hospital-based home care program is highly medical in orientation; the provision of nonmedical support services is not permitted as part of the program. In fiscal year 1989, 72 of the 172 VA medical centers had hospital-based home care programs, and 15,700 veterans were served by these programs (837).

The *adult day health care program* was established as a demonstration program by Public Law 98-160 and provides a "medical model" of adult day services (508,837). The program, which first admitted patients in 1985, provides health care, health maintenance, and rehabilitative services for veterans. In fiscal year 1989, 15 VA medical centers were operating adult day health centers with a total average daily census of 318 (837). In addition, 22 VA medical centers were authorized to contract with community agencies for adult day health care services for veterans, and a total of 396 veterans received contracted adult day health services (837).

Lastly, the *community residential care program* provides room, board, personal care, and supervision to veterans who are not in need of hospital or nursing home care but who cannot live independently. Typically these veterans do not have an informal caregiver. After the VA locates a suitable home and the veteran is placed, VA social workers and nurses provide in-home treatment and case management. In fiscal year 1989, 127 of the 172 VA medical centers had a community residential care program, and the programs provided placement for 11,100 veterans in 2,900 homes (837,917).

Special VA Programs of Particular Relevance for Veterans With Dementia

In addition to the acute and extended-care services just described, some VA medical centers have other programs that are particularly relevant for veterans with dementia and their caregivers. The programs are Geriatric Research, Education, and Clinical Centers; Geriatric Evaluation Units; special care units for veterans with dementia; respite care; caregiver support groups; and special informational materials.

Geriatric Research, Educational, and Clinical Centers (GRECCs) were begun in 1975 to provide basic and clinical research and education and training for clinicians and researchers in the field of geriatrics. Each GRECC focuses on specific areas in geriatric medicine and typically provides care for veterans with diseases and conditions in those areas. As of 1989, there were 10 fully operational GRECCS, four of which were caring for at least some veterans with dementia (76). The sites for two additional GRECCs were selected in 1989, and the two sites received partial funding in that year (8,837).[3] For more than 10 years, the GRECC at the E.N. Rogers Memorial Veterans Hospital, in Bedford, Massachusetts, has been providing inpatient and outpatient care for veterans with dementia through its Dementia Study Unit. Box 6-A describes the services provided by the Dementia Study Unit.

Geriatric evaluation units (GEUs) are hospital units that use a multidisciplinary team to assess elderly veterans and develop a coordinated plan of care for them. GEUs and their counterparts in non-VA hospitals are discussed in chapter 8, and the GEU at the VA Medical Center in Sepulveda, California, is described in box 8-K in chapter 8. As of 1989, there were 87 GEUs in VA hospitals nationwide (917).

GEUs usually consist of a group of VA hospital beds, typically from 4 to 20, that are set aside for comprehensive patient assessment. The objective of a GEU is to refine the diagnosis, treatment, and placement plans for older veterans, particularly those with multiple chronic diseases, remediable impairments, or psychosocial problems. The evaluation can take from 1 to 2 weeks or longer, depending on the complexity and severity of the veteran's

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[3] Although the total number of authorized GRECCS is 25, funds have been appropriated for only 12 GRECCs (8,508).

Box 6-A—The Dementia Study Unit at the E.N. Rogers Memorial Veterans Hospital in Bedford, Massachusetts

The Dementia Study Unit of the Geriatric Research, Education, and Clinical Center at E.N. Rogers Memorial Veterans Hospital provides inpatient and outpatient care for veterans with dementia and information and support for their caregivers. The Dementia Study Unit operates three 25-bed wards and is able to serve 75 veterans on an inpatient basis. The unit has an outpatient caseload of about 40 veterans.

Many of the veterans served by the Dementia Study Unit have been diagnosed at one of the large teaching hospitals in Boston or by a private physician but have not received any followup care from those sources. According to the Dementia Study Unit's social worker, the caregivers of these veterans typically manage without assistance for as long as they can and are often physically and emotionally exhausted by the time they reach the VA. Since the VA is the last place these caregivers turn for help, many of them are seeking inpatient long-term care. They are encouraged to keep the veteran with dementia at home for as long as possible, however.

When the veteran and his or her caregiver are first seen at the Dementia Study Unit, a multidisciplinary team—including a neurologist, a nurse, and a social worker—conducts a complete assessment. The neurologist performs a diagnostic evaluation. The nurse assesses the veteran's physical limitations and functioning, and the social worker conducts a psychosocial evaluation. The assessment is almost always conducted on an outpatient basis. It usually involves several interviews with the caregiver and may involve a home visit.

After the assessment, the veteran and his or her caregiver generally return to the VA for regularly scheduled outpatient visits during which the staff reassesses the veteran's condition and provides information, support, and counseling for the caregiver. These visits also help familiarize caregivers with the inpatient setting and prepare them for the likely institutionalization of the patient later on.

In between scheduled outpatient visits, the social worker maintains telephone contact with the caregivers, and the caregivers are encouraged to call the Dementia Study Unit as the need arises. The social worker considers his main role to be expanding the caregivers' knowledge about dementia, informing them about available services, and helping them improve their coping skills. The social worker circulates a newsletter that contains information about VA and non-VA services. He also assists caregivers in arranging services.

The Dementia Study Unit provides respite care for veterans treated on an outpatient basis. The veterans and their caregivers may use up to 2 weeks of respite care once every 3 months.

Eventually, many of the veterans who are seen as outpatients are admitted to one of the inpatient wards as long-stay residents. For these veterans, the Dementia Study Unit provides medical and nursing care; physical, occupational, recreational, and music therapy; dental care; exercise programs; and other services. Support groups are provided for the caregivers of inpatients and outpatients. The "Wives Support Group" run by the Dementia Study Unit is described in box 6-C.

SOURCES: J. Larkin, clinical social worker, Geriatric Research, Education, and Clinical Center, E.N. Rogers Memorial Veterans Hospital, Bedford, MA, personal communications, Aug. 3, 1988, and July 14, 1989; B. Seltzer, associate director for clinical services, Geriatric Research, Education, and Clinical Center, E.N. Rogers Memorial Veterans Hospital, Bedford, MA, personal communication, Aug. 3, 1988; L. Volicer, K. Fabiszewski, Y. Rheume, et al., *Clinical Management of Alzheimer's Disease* (Rockville, MD: Aspen Publications, 1988).

condition. GEUs often provide comprehensive assessments for veterans with dementia, but some GEUs do not admit veterans with severe, irreversible dementia, especially if the veterans' dementia has been diagnosed and evaluated previously (394,869).

VA special care units are inpatient care settings for veterans with Alzheimer's disease and other dementing diseases. It is estimated that about 40 VA medical centers have special care units. Typically these units are comprised of intermediate medical care beds in a VA hospital. In 1985, VA special care units ranged in size from 18 to 46 beds (855). Evidence from several special care units indicates that most veterans who are admitted to special care units remain there for the rest of their lives due to the general debilitated state of the veteran and the typically overburdened status of the caregiver at the time of admission (82,751). On the other hand, as discussed below, some and perhaps many VA special care units use certain beds on the unit for short-term respite care for veterans with dementia. Box 6-B describes the special care unit at the VA Medical Center in Coatesville, Pennsylvania.

Respite care was offered by approximately 100 VA medical centers as of 1989 (837). In the VA, respite care is strictly limited to an institutional

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Box 6-B—The Alzheimer's Center at the VA Medical Center in Coatesville, Pennsylvania

The Alzheimer's Center at the VA Medical Center in Coatesville, Pennsylvania, is the largest VA special care unit for veterans with dementia. The special care unit has 91 beds on 2 wards. The nursing staff consists of 13 RNs, 6 LPNs, 34 nursing assistants, and a nursing supervisor. Two physicians and one physician assistant provide medical care for residents on the two wards.

The special care unit—like other VA special care units—is usually filled to capacity and has a waiting list. Admission to the unit almost always comes through the VA Medical Center's geriatric evaluation unit. The great majority of residents on the unit are male veterans, but as of May 1989, two of the residents were female veterans. One end of each ward is reserved for veterans with advanced conditions who are confined to a bed or a chair.

The special care unit provides many services in addition to nursing and medical care, e.g., occupational therapy, speech therapy, music therapy, pet therapy, and exercise programs. It has an outdoor fenced-in area that residents are encouraged to use, and many of the residents participate in a horticulture program where they take care of plants and make floral arrangements.

Residents of the special care unit who are ambulatory can take advantage of special outings—such as a May 1989 fishing trip. The unit also has activities that include family members, such as a Father's Day picnic held in June 1989.

The resident's wives and other family members are encouraged to join the family support group that meets once a month for educational presentations and gives family members an opportunity to share their experiences and feelings with one another. Many of the residents' wives also perform volunteer activities on the special care unit.

Sometimes veterans are transferred from the Alzheimer's Center to the VA hospital for acute medical care. Since the special care unit is located in the VA medical center, transfers back and forth to the hospital can be accomplished with greater ease than they can in the non-VA health care sector.

SOURCES: L. Swingler, medical social worker, Alzheimer's Center, VA Medical Center, Coatesville, PA, personal communication, May 23, 1989; C. Curato, ward secretary, Alzheimer's Center, VA Medical Center, Coatesville, PA, personal communication, May 24, 1989; L. Bristol, Alzheimer's Center supervisor, VA Medical Center, Coatesville, PA, personal communication, May 26, 1989.

setting, i.e., a VA hospital or nursing home. The respite care is intended to provide short-term care for the veteran in order to relieve his or her primary caregiver. Each veteran can receive a maximum of 30 days annually, with each admission limited to a maximum of 14 days.

OTA does not know how many VA respite programs serve veterans with dementia, but VA officials report that the implementing guidelines do not preclude serving veterans with dementia (480). At least one respite program designed specifically for veterans with dementia was instituted at the Palo Alto VA Medical Center in 1979 (64). The Dementia Study Unit at the GRECC in Bedford, Massachusetts, described in box 6-A, and the special care unit at the Coatesville, Pennsylvania VA Medical Center, described in box 6-B, both provide institutional respite care for veterans with dementia.

Support groups for spouses and other caregivers of veterans with dementia are provided by some VA medical centers. Box 6-C describes a meeting of the Wives Support Group run by the Dementia Study Unit at the GRECC in Bedford, Massachusetts. Other VA medical centers have support groups for caregivers of veterans with all kinds of disabilities. Still other VA medical centers encourage caregivers to participate in an Alzheimer's Association or other non-VA support group. These support groups afford the caregivers an opportunity to share their experiences in coping with the illness and to give and receive emotional support from the other caregivers.

Some VA medical centers have developed *special informational materials* for caregivers of veterans with dementia. One example is the VA Medical Center in Minneapolis, Minnesota, which has developed a series of booklets on topics of importance to caregivers of veterans with dementia, including "What is Alzheimer's Disease?" "The Role of the Caregiver," "Managing From Day-to-Day," and "Working With Bureaucracies."

VA Education, Training, and Research Programs

In addition to providing and paying for health care and health-related services for veterans, the VA's VHS&RA also has two other functions: providing education and training for health care professionals

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Box 6-C—The Wives' Support Group at the E.N. Rogers Memorial Veterans Hospital in Bedford, Massachusetts

One OTA staff member attended the August 3, 1988 meeting of the Wives' Support Group run by the Dementia Study Unit at the E.N. Rogers Memorial Veterans Hospital in Bedford, Massachusetts (see box 6-A). At the time of the meeting, with one exception, each of the husbands of the women who attended the meeting were long-stay residents of the Dementia Study Unit's inpatient wards. The remaining husband was enrolled in the Dementia Study Unit's outpatient program and was being cared for at home by his wife, awaiting an opening on one of the inpatient wards.

Of all the many stories that unfolded during the meeting of the Wives' Support Group, the most striking was the similar scenario portrayed by each woman of her experience seeking help in the non-VA health care sector, which eventually ended with her finding out about the VA's special Alzheimer's program completely "by accident." Before finding out about the VA program, all but one of the wives had taken their husbands to the family doctor and were referred to a neurologist. All the wives said that after the neurologist confirmed the Alzheimer's diagnosis, they did not receive any information about what to do from there. One woman stated that she was actually relieved by the diagnosis, but they all admitted that Alzheimer's was a difficult disease to come to terms with, and many said they felt "abandoned" by the non-VA health care system.

The wives' stories about how they found out about the VA's special Alzheimer's program all included the common theme of having found the program "by accident." One woman said that, by chance, she saw a TV program that mentioned the VA program. Another heard about the VA through a friend. A third woman had a daughter who had worked previously at the Bedford VA hospital, and another had seen a TV Guide listing on a memory program that talked about the Geriatric Research, Education, and Clinical Center at the VA hospital. Only one woman had learned about the program by contacting the VA directly.

As noted above, only one member of the support group was still caring for her husband at home. She said that she was dependent on the support group for reassurance and could not imagine having to go through any more of the "ordeal" without the help of the support group. At one point, she tearfully explained how frightened she is when her husband, who is apparently much larger than she, becomes confused and agitated—all the while not knowing who she is. All the other wives understood.

Another wife of a World War I veteran attempted to explain the tremendous guilt she felt when her husband was still at home and she needed help. She said she did not feel that she should "bother" her children to give her a hand. Now, years later, she still feels guilty, despite the fact that her daughter, who attended the meeting with her, assured her that all her children wanted to help.

The wives agreed that since they found the VA program, they were "saved" from an "awful" existence. The program offered them the solace, advice, coping mechanisms, and the services they needed to survive the time that their husbands were outpatients. The VA program gradually acquainted them with the inpatient unit and gave them a comfortable familiarity when the time came to admit their husbands to the inpatient wards.

SOURCE: Wives Support Group, Geriatric Research, Education, and Clinical Center, E.N. Rogers Memorial Veterans Hospital, Bedford, MA, Aug. 3, 1988.

and sponsoring medical research. These two functions are important for veterans with dementia because some of the education and training and research programs focus on Alzheimer's and related dementias.

The VA conducts the largest education and training effort for health professionals in the United States and is the principal training resource in geriatric medicine (854,857). Annually, through affiliations with over 1,000 educational institutions, including schools of medicine, nursing, and other health professions, about 100,000 students, including about half of the physicians in this country, receive some or all of their clinical training through the VA (507).

In fiscal year 1988, the VA supported about 8,350 full-time medical residency positions, with geriatrics among the areas receiving special emphasis (76). A significant number of nursing students receive VA scholarships for training in geriatric/gerontological nursing (831). Many of these individuals have contact with dementia-specific programs and/or veterans with dementia.

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Veterans Administration
Respite Care: When You Need
A Guide for Families C Persons with Dementia Diseases
Working with Financial and Legal Advisors:
Working with Bureaucra What to do?
A Guide for Families Caring for Persons with Dementia-Related
Working with Financial ar Legal Advisors
Guardianships and Involuntary Treatment
What To Do? A Guide for Families Caring for Persons with Dementia-Related Diseases
The Move to a Nursing H
What to do? A Guide for Families Persons with Dement Diseases
Choosing a Nursing Home
Institutional Care
rking With Health Care ofessionals
Special Care Problems Part 1:
Restlessness, Wanderin and Sleep Disturbances
What To Do? A Guide for Famili Caring for Persons with Dement Related Diseases
Working with Fi Legal Advisor for Now and
What to do? A Guide for Persons w Disease

Photo credit: Gretchen Kolsrud

The VA Medical Center in Minneapolis, Minnesota, has developed a series of informational booklets for caregivers of people with dementia.

As noted earlier, GRECCs provide training for clinicians in the field of geriatrics. The VA Interdisciplinary Team Training Program in Geriatrics also provides clinical training in geriatrics for students in various health disciplines, such as nursing, psychology, and social work, to develop knowledge and skills in providing interdisciplinary team care. In 1988, the Interdisciplinary Team Training Program in Geriatrics funded support for almost 200 health professionals from various disciplines (76).

The VA's Office of Research and Development in the VHS&RA each year funds over 4,000 researchers with a budget of approximately $200 million (76). For fiscal year 1988, over $2.6 million of the VA's total research budget was devoted to research pertaining to dementia. In addition, VA researchers reported receiving another $2.9 million for dementia-related projects from non-VA sources.

Summary and Implications

The preceding section has described many VA services that may be helpful for veterans with dementia and their caregivers, including some services specifically designed for veterans with dementia. That these services exist highlights the importance for veterans with dementia and their caregivers of effective methods by which they can be linked to VA services for which they are eligible.

On the other hand, the information just presented makes it clear that the VA does not provide all the services that may be needed for veterans with dementia. Certain services, e.g., in-home respite care, are not provided by the VA at all. Other potentially helpful services are provided by some VA medical centers and not others. As of 1989, for example, approximately 100 of the 172 VA medical centers provided institutional respite care, and 15 of the 172 centers had adult day health care programs. One reason for the differences among VA medical centers in the services they provide is that VA medical centers have some discretion about which services they provide.[4] Institutional respite care is a service that each VA medical center has the option to provide. Another reason for the differences among VA medical centers in the services they provide is that Congress, faced with budget constraints, sometimes authorizes and/or funds the provision of certain services at only a few VA medical centers. Adult day health care is a program that only a few VA medical centers are authorized to provide.

The great majority of VA health care and health-related services are provided at VA medical centers, which means that the services are more readily accessible by veterans who live near one of the medical centers. The 172 VA medical centers are not uniformly distributed across the country, and some have very large catchment areas (662,724). As a result, some veterans and their caregivers have to travel long distances to access VA services, and some may not be able to access VA services (481,662,823). This problem is exacerbated when the needed services are not provided by the nearest VA medical center.

As noted earlier, some people believe that the VA should provide more services of various kinds, and other people believe that the VA cannot or should not provide more services. This OTA assessment does not address the question of what services the VA should provide. In the context of this assessment, the fact that the VA does not provide all the services that may be needed for veterans with dementia points to the importance of effective methods by which veterans with dementia can be linked to non-VA services. The fact that some veterans live too far from a VA medical center to access VA services underscores the importance of those methods.

Many of the extended-care services provided by the VA are institutional or residential in nature. With respect to the care of elderly veterans in general, the VA has been criticized for overemphasizing institutional services and underemphasizing in-home and other noninstitutional services (8,481,509,662). These same criticisms are generally relevant to the care of many veterans with dementia. On the other hand, institutional and residential care services are appropriate for some veterans with dementia who have no relative or other informal caregiver to help them and for some veterans with dementia whose relatives and friends are unable to take care of them.[5] That the VA provides primarily institutional and residential extended-care services emphasizes the importance of effective methods of linking veterans with dementia who need such services to the VA and, conversely, the importance of linking veterans with dementia who need services not available from the VA to non-VA service providers.

The VA is sometimes also criticized for overemphasizing medically oriented services and underemphasizing nonmedical, supportive services (8). Veterans with dementia need both medical and nonmedical services. Some people believe that the VA should provide more nonmedical, supportive services. In the context of this OTA assessment, however, the fact that the VA provides more medically oriented services reinforces the need for effective methods of linking veterans with dementia who need such services to the VA and effective methods of linking veterans with dementia who need nonmedical, supportive services to non-VA providers if these services are not available from the VA.

PROBLEMS IN LINKING VETERANS WITH DEMENTIA TO VA SERVICES

Some people, including some veterans and their families, believe that the VA will provide all the health care and long-term care services the veteran needs and that the veteran will be able to obtain these services simply by virtue of the fact that he or she is a veteran. The preceding section pointed out that some of the services that may be needed for veterans with dementia are not available from the VA at all or are only available from certain VA medical centers. This section discusses problems in linking veterans with dementia to services that *are* available from the VA. The discussion focuses on the complexity of the eligibility criteria for VA services, the difficulty of determining whether a veteran with dementia will receive VA services, and the lack of accurate information about what services are available. All three of these problems are frustrating for families and others who are trying to plan and arrange services for a veteran with dementia.

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[4] The VA's planning process (called Medical District Initiated Program Planning—MEDIPP) allows each VA medical center some degree of discretion about the type and amount of services it will offer. The MEDIPP process then coordinates the individual medical centers' plans at the district level.

[5] In response to congressional requests and a mandate of Public Law 99-576, the VA prepared a report on "Alternatives to Institutional Care," which was presented to Congress in January 1988 (860). The report describes the VA's noninstitutional services for elderly veterans and veterans with chronic mental illness, including various pilot and demonstration projects intended to evaluate the effectiveness of noninstitutional services for these patient groups. The report points out the importance of institutional care for some types of veterans.

The Complexity of the Eligibility Criteria for VA Services

In 1986, Congress passed Public Law 99-272, which substantially revised the eligibility criteria for VA health care and health-related services. The law specified three categories of veterans—"A," "B," and "C"—for the purposes of eligibility determination. The law mandated a means test for certain veterans and certain services and, for the first time, required the VA to provide hospital care for certain veterans. In 1988, Congress passed Public Law 100-322, which further revised the eligibility criteria for outpatient care. The resulting criteria are extremely complex. Although the eligibility criteria for VA services can be and frequently are summarized in one or two paragraphs, such a summary fails to convey a true sense of their complexity. Since that complexity is one of the major problems in linking veterans with dementia to VA services, the eligibility criteria are described in greater detail here.

The three categories of veterans specified by Public Law 99-272 are as follows:

Category A includes any veteran who:

- has a service-connected disability;
- is a former prisoner of war;
- served during the Spanish-American War, Mexican border period, or World War I;
- may have been exposed to certain toxic substances while on active duty in Vietnam;
- may have been exposed while on active duty to ionizing radiation from nuclear testing or participation in the American occupation of Hiroshima or Nagasaki, Japan;
- has an income below $15,833 for a single veteran and $18,999 for a married veteran, plus $1,055 for each additional dependent[6];
- is eligible for Medicaid; or
- receives a VA pension.

Category B includes any veteran who does not have a service-connected disability, does not meet the other criteria for category A, and has an annual income between $15,833 and $21,110 for a veteran with no dependents and between $18,999 and $26,388 for a veteran with dependents.

Category C includes any veteran who does not have a service-connected disability, does not meet the other criteria for category A, and has an annual income over the category B amounts.

Determining whether a veteran is eligible for and will receive a service is complicated not because of the three categories just listed, but because of other factors that affect the determination. One of the factors is whether the condition for which the veteran needs treatment or services resulted from military duty (i.e., whether the condition is service-connected). Another factor is what services the veteran needs. The VA is required to provide certain services for certain veterans, as discussed below, but most services for most veterans must be provided only on a "space available" basis. Thus, the services are not an entitlement; a veteran's eligibility for them is not absolute but, instead, depends on whether there is "space available" in the service program (641,741). As a result, a given veteran might be determined to be eligible for and receive a given service from one VA medical center that had "space available" but not from another VA medical center that did not have "space available." Lastly, the eligibility criteria for regular VA services are sometimes waived for services provided as part of a research or demonstration program. The following sections describe the eligibility criteria for many of the kinds of services described earlier in this chapter as potentially helpful for veterans with dementia.

Hospital Care

Public Law 99-272 required that the VA provide free hospital care for any category A veteran who:

- is being treated for a service-connected disability;
- has a service-connected disability and is being treated for any disability;

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[6] The dollar figures in this section are for 1988. The figures for subsequent years are adjusted in the same manner as VA pensions.

- was discharged or released from active duty due to a disability incurred or aggravated in the line of duty and is being treated for any disability;
- has a disability resulting from VA treatment or the pursuit of vocational rehabilitation and is being treated for any disability;
- has a service-connected disability rated at 50 percent or more and is being treated for any disability;
- is a former prisoner of war and is being treated for any disability;
- served in the Spanish-American War, Mexican border period, or World War I and is being treated for any disability;
- may have been exposed to certain toxic substances while on active duty in Vietnam or to ionizing radiation from nuclear testing or participation in the American occupation of Hiroshima or Nagasaki, Japan, and is being treated for a condition possibly related to that exposure; or
- has a nonservice-connected disability and is unable to defray the cost of medical care, including:
  a. veterans who receive VA pensions,
  b. veterans who are Medicaid eligible, and
  c. veterans with yearly incomes below $15,833 for a single veteran and $18,999 for a married veteran, plus $1,055 for each additional dependent.

All other veterans may be eligible for VA hospital care at the discretion of the VA medical center and if there is space is available. Category B veterans may be eligible for free hospital care if there is space available. Category C veterans may be eligible for hospital care if there is space available and if they pay a deductible. In 1988, the deductible was $540 for the first 90 days, and $270 for each subsequent 90-day period up to a maximum of $1,350 a year (76).

Outpatient Care

Public Law 100-322 required that the VA provide outpatient care for any category A veteran who:

- is being treated for a service-connected disability,
- has a service-connected disability rating of 50 percent or more, or
- is disabled as a result of VA treatment or in pursuit of vocational rehabilitation (817).

Public Law 100-322 further required the VA to provide, as medically indicated, outpatient services in preparation for, as followup to, or to obviate the need for, hospital admission for any veteran who:

- has a 30 percent or 40 percent disability rating, or
- has an annual income below $9,940 (a figure that is increased by $1,055 for each dependent and is adjusted annually) (817).

The VA may provide outpatient care for some other veterans in preparation for, in followup to, or to obviate the need for hospital admission in the following order of priority.

Priority Group I: any category A veteran who:

1. has a service-connected disability rated at less than 30 percent or needs a compensation or pension examination;
2. is a former prisoner of war or was exposed to toxic substances in Vietnam or ionizing radiation from a nuclear explosion;
3. served in World War I or the Mexican border period or is receiving an "aid and attendance" pension or a similar VA pension; or
4. has income greater than $9,940 and less than the category A threshold (e.g., $15,833 for single veterans) (817).

Priority Group II: any category B veteran.

Priority Group III: any category C veteran who agrees to pay a copayment of $25 per visit.

Nursing Home Care

Nursing home care is a discretionary benefit that may be given to all veterans to the extent that space and funding are available—as long as it is given in the following priority order:

Priority Group I: any category A veteran who:

1. has a service-connected disability and is being treated for any condition;
2. was discharged or released from active duty due to a disability incurred or aggravated in the line of duty and is being treated for any condition;
3. has a disability resulting from VA treatment or in pursuit of vocational rehabilitation and is being treated for any condition;
4. is a former prisoner of war and is being treated for any condition;

5. may have been exposed to certain toxic substances while on active duty in Vietnam or to ionizing radiation from a nuclear test or participation in the American occupation of Hiroshima or Nagasaki, Japan, and is being treated for a condition possibly related to that exposure;
6. served in the Spanish American War, the Mexican border period, or World War I and is being treated for any condition;
7. has a nonservice-connected disability and is unable to defray the cost of medical care otherwise, including:
   a. veterans who receive VA pensions,
   b. veterans who are Medicaid eligible, and
   c. veterans with yearly incomes below $15,833 for a single veteran and $18,999 for a married veteran, plus $1,055 for each additional dependent.

Priority Group II: any category B veteran.

Priority Group III: any category C veteran who agrees to pay the deductible.

Care in a VA nursing home is free for veterans in priority groups I and II. Veterans in priority group III must pay a copayment. Length of stay in a VA nursing home is not restricted for veterans in any of the three priority groups. Veterans in any of the three groups can be admitted to a VA nursing home from their home, a hospital, or a residential care setting.

Care in a non-VA nursing home through the VA's community nursing home program (described in the previous section) is also free for veterans in priority groups I and II. Veterans in priority group III must pay a copayment. Length of stay in a non-VA nursing home is not restricted for veterans being treated for a service-connected disability and veterans who were previously hospitalized primarily for the treatment of a service-connected disability. For all other veterans, care in a non-VA nursing home is restricted to 6 months, and many VA medical centers limit the allowed length of stay to 2 to 3 months.[7]

Except for veterans being treated for service-connected disabilities, veterans admitted to a non-VA nursing home through the community nursing home program must be admitted from a VA hospital. This requirement sometimes poses a problem for veterans with dementia who need nursing home care: the problem arises because VA hospitals may not consider a cognitive impairment alone as a sufficient reason for hospital admission, and veterans with dementia may not have an acute illness or another condition that would justify hospital admission.

Domiciliary Care

Veterans who need domiciliary care can qualify if their annual incomes are below the "aid and attendance" pension level—$9,940 for the veteran without dependents (a figure that is increased by $1,055 for each dependent and is adjusted annually), or if, as determined by the Secretary, they have no adequate means of support. In clarifying these eligibility criteria, the conferees for the Veterans' Benefits and Services Act of 1988 stated that veterans with service-connected disabilities should be given first priority and that income alone should not be used to deny them eligibility for domiciliary care (817).

Eligibility Criteria for Other VA Programs

VA research and demonstration programs and some other VA programs often provide services for veterans who would not necessarily be eligible for VA services under the general eligibility criteria. With respect to GRECC programs, for example, a veteran whose situation "fits" into the research being conducted by the GRECC can be admitted to the program, regardless of whether the veteran meets other eligibility criteria. In order to qualify for the inpatient and outpatient care provided by the Dementia Study Unit at the GRECC in Bedford, Massachusetts (see box 6-A), a veteran must have a diagnosis of Alzheimer's disease (440). If this criterion is met, the veteran can be admitted into the program and receive free services whether or not he or she has a service-connected disability or a qualifying income level. Likewise, VA special care units can admit veterans on the basis of their diagnosis or condition, independent of the general eligibility criteria for VA hospital or nursing home care.

Situations like these in which the general eligibility criteria for VA services are not strictly applied add to the complexity of VA eligibility criteria.

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[7] A veteran with dementia who has a service-connected disability unrelated to the dementia would not qualify for unrestricted nursing home care in a non-VA nursing home unless the care were needed for the veteran's service-connected disability.

Although one would not want to require VA research and demonstration programs and other special programs to admit only veterans who meet the general eligibility criteria for VA services, it is easy to understand why the existence of completely different sets of eligibility requirements for apparently similar services might be confusing for families and others who are trying to locate and arrange services for a veteran with dementia.

The Difficulty of Determining Whether a Veteran With Dementia Will Receive VA Services

The complexity of the eligibility criteria for VA services—especially as the criteria interact with the factor of "space availability"—make it difficult to determine whether a veteran with dementia will receive VA services. With the exception of the hospital and outpatient services that the VA is now mandated to provide for some veterans, most VA services, including the extended-care and special services discussed earlier in this chapter, are provided on a "space available" basis. Since the availability of specific kinds of VA services usually cannot be known with certainty much before the time when the services are to be used, it may be difficult, if not impossible, for families and other informal caregivers to know in advance whether a veteran with dementia will receive the services.

The factor of space availability is important in determining whether veterans with all kinds of disabilities will receive VA services, but it may be especially important for veterans with dementia. As is obvious from the preceding review of the eligibility criteria for VA services, veterans with service-connected disabilities have the highest priority for VA services. Since most diseases that cause dementia occur late in an individual's life, long after he or she is discharged from military service, dementia is seldom considered a service-connected disability (724). Some veterans with dementia have another service-connected disability or meet one of the other previously listed criteria that give an individual high priority for receiving VA services. For veterans with dementia who do not meet any of these criteria (e.g., all category B and C veterans), space availability is a major factor determining whether they will receive VA services.[8]

The availability of VA services is affected by both the supply of and the demand for services. The supply of all VA services depends on the funds available to the VA as a whole and to individual VA medical centers. The supply of specific kinds of services depends on decisions at the national, district, and individual VA medical center level in regards to which services will be funded. The demand for VA services depends on the number of veterans who need the services, the availability and cost to the veteran of non-VA services, veterans' and their families' awareness of VA and non-VA services, their perception of the relative quality of VA v. non-VA services, and other factors (641, 662,741).

Since the availability of VA services is determined by the supply of and the demand for services, availability changes in response to changes in both the factors that affect supply (e.g., the funds available to the VA) and the factors that affect demand (e.g., the number of veterans who need services). A full analysis of these factors is beyond the scope of this OTA assessment. It is clear, however, that current pressures to contain Federal spending are placing limits on the funds available to the VA. At the same time the VA is faced with increased demand for services because of the growing number of older veterans (8,490,815,820,854). The number of veterans over age 65 increased from 3 million in 1980 to 7 million in 1990 and is expected to increase to 9 million by the year 2000 (854). Historically, veterans have relied primarily on non-VA services. From 1979 to 1981, for example, only 13 percent of all veterans' hospitalizations were in VA hospitals (823). That could change, however, if the cost of non-VA services increased or their availability or quality decreased (741).

Spurred by an awareness of the increasing number of older veterans, the VA and other government agencies have tried to project the future demand for VA services (805,824). In 1984, the VA published a report projecting future demand and setting goals for specific VA programs considered important in caring for older veterans (e.g., GRECCs, GEUs, hospital-based home care, adult day health care, and community residential care).[9] With the exception of hospital-based home care, the VA is far from reaching its 1990 objectives for these programs.[10]

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[8] In 1984, about 30 percent of the veterans treated in VA hospitals had a service-connected disability, and 70 percent did not. On one particular day, Sept. 30, 1984, 16 percent of the veterans treated in VA hospitals were being treated for a condition related to their service-connected disability, and 84 percent were being treated for a nonservice-connected condition (823). OTA is not aware of more recent data on these issues. Presumably, however, if there has been an increase since 1984 in the proportion of veterans being treated in VA facilities who are being treated for a service-connected disability or who at least *have* a service-connected disability, veterans with dementia who do not have a service-connected disability are less likely to receive services.

The preceding discussion suggests that the supply of certain VA services is unlikely to meet the demand for the services on a national level and that veterans with dementia who do not have a service-connected disability and do not meet one of the other criteria that give an individual high priority for receiving discretionary VA services may be unlikely to receive the services. During testimony at a hearing in April 1989, representatives of two veterans organizations testified that some VA medical centers were turning away category B and C veterans (490,882). One representative of a service organization said that several VA medical centers have publicly announced the discontinuance of all types of care for category B and C veterans (490). On the other hand, the supply of and demand for VA services varies at different VA medical centers, and as discussed earlier, the eligibility criteria for different VA services also vary. Despite the problems of space availability, therefore, it is likely that some, and perhaps many, veterans with dementia will continue to receive VA services.

The Lack of Information About VA Services

As noted in the beginning of this chapter, OTA has heard complaints from some caregivers of veterans with dementia about the difficulty of finding out what services are available from the VA. Anecdotal evidence suggests that many veterans and their families are not knowledgeable about what services are provided by the VA. In the course of this study, it has become clear to OTA staff that many non-VA health care and social service professionals, service providers, information and referral agencies, case managers, and others who refer people with dementia to services also are not knowledgeable about VA services. This lack of knowledge includes both a lack of general awareness of services, referred to as *service consciousness* in this report, and a lack of knowledge about specific services, referred to as *service knowledge* in this report.

OTA is not aware of any research on how families and other informal caregivers of veterans with dementia, who are eventually linked to VA services, find out about the services. VA medical centers frequently have printed brochures that describe the services they provide, but these brochures seem to be of only limited utility for caregivers of veterans with dementia. Anecdotal evidence indicates that some caregivers find out about potentially helpful VA services by contacting a VA medical center directly. Other caregivers find out about such services from veterans organizations that may not only give them information about services but also help them obtain the services. Still other caregivers find out about VA services from a non-VA health care or social service professional, service provider, or case manager who has previously learned about the services from another client, a professional meeting, or another source. OTA does not know how many caregivers learn about VA services in any of these ways. Often, however, it seems that caregivers find out about potentially helpful VA services in completely haphazard ways. As described in box 6-C, all but one of the members of the Wives Support Group at the E.N. Rogers Memorial Veterans Hospital in Bedford, Massachusetts, said they found out about the special Alzheimer's program at the VA hospital "by accident," from a friend, an acquaintance, or a TV program they happened to watch. Probably some caregivers only learn about some of the VA's extended-care services and the special VA programs described in this chapter after their relative or friend with dementia has been admitted to a VA hospital for an acute medical condition.

Given the variation among VA medical centers in the amount and kinds of services they provide and the complex issue of space availability that affects what services are really available though a VA medical center, it is easy to understand why there would be a lack of accurate information about VA services. Until recently, the VA itself has not been fully aware of the kinds of services it is providing for veterans with dementia. In 1988, the VA conducted a survey of all 172 VA medical centers to find out what programs and services were available for veterans with dementia (76). The results of the survey have been compiled into a directory for internal VA use in referring veterans and their caregivers to services and responding to public inquiries about the location of services for veterans with dementia across the country. It is hoped that the directory will allow the VA to provide more accurate information about services (76). The directory cannot solve the problem of determining whether an individual veteran with dementia will actually receive VA services, however, because that determination depends to a great extent on space availability at the time the veteran needs the services.

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[9] The projections in the VA's 1984 report were made before the 1986 and 1988 revisions to the eligibility criteria for VA services. OTA is not aware of any projections of future demand for VA services that take those revisions into consideration.

[10] Currently, with hospital-based home care programs at 73 medical centers, the VA is close to its 1990 goal of 76 medical centers with hospital-based home care programs. Only 87 VA medical centers have GEUs, still 33 short of the 1990 goal of 120 centers. There are 12 GRECCs, 18 GRECCs shy of the 1990 goal of 30. Adult day health care is available through 15 VA medical centers, 25 below the 1990 goal of 40 programs. Community residential care is available through 127 VA medical centers, although the 1990 goal was to have that program in effect in all 172 VA medical centers (854,917).

Summary and Implications

The complexity of the eligibility requirements for VA services, the difficulty of determining whether a veteran with dementia will receive VA services, and the lack of information about VA services complicate the process of linking veterans with dementia to VA services. Anecdotal evidence indicates that many caregivers of veterans with dementia do not know what VA services are available and do not know how to find out. As a result, some caregivers may not apply for services the veteran needs and could receive from the VA. Other caregivers may assume mistakenly that the VA will provide the needed services. When these caregivers finally do apply to the VA for services—often very late in the course of the veterans' illness when the caregiving situation has become unmanageable—they may find that the services they need are not available, that the veteran is not eligible for the services, or that the programs that provide the needed services are full.

The recently completed directory of VA services for veterans with dementia should allow the VA to provide more accurate information about services. With the exception of certain services now mandated for certain veterans, however, most VA services are provided on a "space available" basis. Since space availability cannot be determined much before the time when the veteran will use the services, families and other informal caregivers generally cannot know in advance whether the veteran will receive VA services. This is true of the extended care services and many of the special VA programs described earlier in this chapter. Without that information, families and others cannot plan ahead for the care of a veteran with dementia.

Some caregivers of veterans with dementia contact the VA directly for information about services, but other caregivers would be unlikely to contact the VA unless they were referred by another source. The same factors that make it difficult for caregivers to know about potentially helpful VA services also make it difficult for non-VA health care and social service professionals, service providers, information and referral agencies, case managers, and others who refer people with dementia to services to know about VA services. Anecdotal evidence suggests that some individuals who refer people with dementia to services have an informal connection to someone at the VA and contact that person from time to time when they need information about VA services (404), but many agencies and individuals that refer people with dementia to services probably do not have such a contact at the VA and may not know how to find out about VA services.

Over the years, the VA has participated in several cooperative initiatives with other community agencies, one purpose of which has been to inform the other agencies about VA services so that they can provide accurate information about VA services for veterans they may see as clients. Some VA medical centers and area agencies on aging (AAAs) have worked together to develop information and referral procedures to help the AAAs make appropriate referrals for VA services (662). Facilitating appropriate referrals of veterans to the VA for services is also one of the positive outcomes of many of the "sharing agreements" discussed later in this chapter.

Finally, with respect to the policy question of the role of the VA in relationship to a national system to link people with dementia to services, it is clear that *only the VA can finally link veterans with dementia to VA services.* Non-VA health care and social service professionals, service providers, information and referral agencies, and case managers can refer veterans with dementia to the VA, and these referrals can be more or less appropriate. Likewise, a non-VA linking system could refer veterans with dementia to the VA. Given the complexity of the eligibility requirements for VA services, however, especially as they interact with the factor of space availability, it is clear that the VA must determine whether a veteran will receive VA services and which services he or she will receive. These functions cannot be performed by the non-VA linking system, and this OTA report does not consider that an option.

PROBLEMS IN LINKING VETERANS WITH DEMENTIA TO NON-VA SERVICES

Although the VA provides many of the services that may be needed for veterans with dementia, some veterans with dementia are not eligible for VA services, and some services that are needed for people with dementia are not available from the VA or are only available from certain VA medical centers. As a result, many veterans with dementia are likely to need non-VA services as well.

The VA has at least four mechanisms by which it links veterans to non-VA services. Two of these mechanisms—hospital discharge planning and case management—directly link individual veterans to non-VA services. The other two mechanisms—"sharing agreements" and the functions of the "community services coordinator" at each VA medical center—generally coordinate VA and non-VA services, thereby indirectly facilitating veterans' access to non-VA services. This section briefly describes each of the four mechanisms and discusses problems that may interfere with their effectiveness. The section also identifies certain types of veterans who are unlikely to be linked to non-VA services through the four mechanisms.

It is interesting to note that although some people believe that the VA should provide the full range of health care, long-term care, and other services needed for all veterans, the VA often describes its role as providing certain services and attempting to ensure that veterans have access to the other services they need through the four mechanisms discussed in this section (837,860). In that sense, hospital discharge planning, case management, community services coordination, and joint initiatives with non-VA agencies are the means by which the VA tries to promote continuity of care and ensure the availability of comprehensive services for veterans even though it cannot provide all the services directly.

VA Mechanisms for Linking Individual Veterans to Non-VA Services

The Social Work Service at each VA medical center has primary responsibility for linking individual veterans to non-VA services and implements that responsibility largely through hospital discharge planning and case management. Veterans who need non-VA services can come to the attention of the Social Work Service in several different ways:

- veterans who are receiving inpatient care in a VA hospital may be referred to or identified by the Social Work Service as needing hospital discharge planning;
- veterans who are receiving extended-care services through certain VA programs routinely receive case management, which is usually provided by the Social Work Service;
- veterans who apply to a VA medical center for services but are denied VA services for any reason (e.g., they are not eligible, there is no space in the service program, or the VA medical center does not provide the services they need) may be referred by the admissions office to the Social Work Service; and
- veterans and their families who are not receiving any VA services may contact the Social Work Service directly for assistance in finding non-VA services.

Each VA medical center has a policy for hospital discharge planning. Within that policy, the Social Work Service is required to have discharge planning procedures that include:

- the provision of a multidisciplinary assessment;
- the development of a plan of care that incorporates quality of life concerns;
- the involvement of the veteran, the veteran's family, and significant others in discharge planning;
- the provision of referrals to non-VA service providers and assistance in arranging non-VA services; and
- the provision of referrals to VA extended-care services (858).

In fiscal year 1987, VA social workers provided hospital discharge planning for 420,000 veterans (857).

VA case management includes the five functions identified by OTA as core case management functions (i.e., client assessment, care planning, service arrangement and coordination, monitoring, and reassessment), plus screening (236). The VA routinely provides case management for veterans who are receiving extended-care services through certain VA programs, such as the hospital-based home care program, the community nursing home program, and the community residential care program. The

Social Work Service generally has primary responsibility for the provision of case management in these programs, but in some instances, the case manager may be a VA nurse or another member of the treatment team, depending on the veteran's needs (236). In these programs, case management includes arranging and coordinating both VA and non-VA services (858).

The Social Work Service at each VA medical center is required to identify veterans in certain "at risk" categories and to provide hospital discharge planning and case management for them, as needed (858). Veterans with dementia might be included in several of the "at risk" categories, e.g., "chronically ill," "incompetent," or "age 70, disabled, and living alone." OTA is not aware of any data on the number of veterans with dementia who receive hospital discharge planning or case management through the VA.

VA hospital discharge planning and case management are provided primarily for veterans who are already receiving or are eligible for VA services: by definition, VA hospital discharge planning is provided for veterans who are receiving inpatient care, and VA case management is provided most often for veterans who are receiving VA extended-care services. On the other hand, the Social Work Service at each VA medical center is not strictly limited to helping veterans who are already receiving or are eligible for VA services (620). Two situations in which VA social workers might assist veterans who are not already receiving or eligible for VA services were noted earlier: 1) situations in which veterans who apply for but do not receive VA services for any reason are referred by the admissions office to the Social Work Service, and 2) situations in which veterans or their families contact the Social Work Service directly for assistance in finding non-VA services (620). OTA does not know how frequently either of these situations occur. VA social workers are probably more likely to provide information and referrals than comprehensive case management in these situations.

Four software programs have been developed by the Social Work Service Special Interest Users Group to assist VA social workers with discharge planning and case management. The four programs are:

- *The High-Risk Screening Program*, which is intended to identify veterans who are most likely to need social work services, including discharge planning and case management;
- *The Case Registry System*, which is intended to help social workers keep track of veterans throughout the course of their care;
- *The Community Resources Managers Program*, which is intended to help the Social Work Service at each VA medical center maintain an accurate and easily accessible list of non-VA services and service providers by type and geographic location of the provider; and
- *The Contract Nursing Home Budget and Census System*, which is intended to help social workers maintain information about VA patients in non-VA nursing homes under contract with the VA (236,856).

Problems in Linking Individual Veterans to Non-VA Services

According to several sources, one of the most difficult problems encountered by the VA in linking individual veterans to non-VA services is the complexity and fragmentation of non-VA services at the community level—the same problem encountered by anyone who tries to locate and arrange services in many communities (481,854,860). Although some VA medical centers are using the Community Resources Managers Program software or other systematic procedures to develop and maintain an accurate list of non-VA services, obtaining the necessary information to keep the list up-to-date can be time-consuming and difficult, just as it is time-consuming and difficult for non-VA information and referral agencies, case managers, and others.

The complexity and fragmentation of non-VA services at the community level exists irrespective of the mechanisms by which the VA links individual veterans to non-VA services, but two other problems in linking individual veterans to non-VA services are related to those mechanisms. One problem is that the VA mechanisms for linking individual veterans to non-VA services are available primarily, although not exclusively, to veterans who are already receiving or are eligible to receive VA services. Many veterans with dementia are unlikely to receive or to be eligible for VA services and therefore may not receive help from VA social workers in finding non-VA services.

A second problem is that the mechanisms by which the VA links individual veterans to non-VA services are more easily implemented for veterans who live near a VA medical center, but some VA medical centers have a very large catchment area, and many veterans in their catchment areas live far from the center. In general, it is probably more difficult for the Social Work Service at a VA Medical Center to maintain an accurate list of non-VA services for geographic areas that are far from the VA medical center than for areas near the center. Likewise, it is more difficult for VA social workers to provide case management for veterans who live far from the medical center. As a result, these veterans may not receive adequate assistance from the VA in linking to non-VA services.

The Minneapolis VA Medical Center has developed a case management program that successfully addresses the latter problem (316). The case management program serves veterans in three areas that comprise 23 primarily rural counties in south central and southeastern Minnesota and 16 primarily rural counties in western Wisconsin. The program is intended to help frail elderly veterans obtain the VA and non-VA services they need to live independently and avoid premature institutionalization. The VA has assigned a VA social worker to each of the three designated areas to provide outreach, case management, caregiver support, and patient advocacy.

VA Mechanisms for Coordinating VA and Non-VA Services

In addition to hospital discharge planning and case management, the VA has at least two mechanisms by which it attempts to coordinate VA and non-VA services and thus indirectly facilitate veterans' access to non-VA services. One of these mechanisms is "sharing agreements" between VA medical centers and non-VA agencies in which the non-VA agencies provide services for veterans in exchange for information, technical assistance, consultation, and other services from the VA medical center. Although there were informal arrangements for sharing resources and expertise between VA medical centers and non-VA agencies before 1975, official support for formal "sharing agreements" began in 1975 with a working agreement between the VA and the Administration on Aging (820). One sharing agreement between a VA medical center and an AAA in West Virginia is described in box 6-D.[11]

The second mechanism by which the VA attempts to coordinate VA and non-VA services is through the designation of "community services coordinators" who are intended to be the focal point for contact between the VA and non-VA agencies (859). Since 1985, the VA has required the Social Work Service at each VA medical center to identify a community services coordinator. The functions of the community services coordinator are as follows:

- to identify and assess existing non-VA health care, social, and volunteer services;
- to coordinate and integrate the VA's services and activities with the non-VA health and social services network, including AAAs;
- to make available the full range of non-VA services to aging veterans and their caregivers;
- to facilitate VA staff involvement in joint activities with AAAs and other community agencies, including program development, sharing services, and cooperative planning;
- to integrate and link non-VA resources into the VA's Medical District Initiated Program Planning (MEDIPP) process; and
- to facilitate joint development of health education and disease prevention programs (859).

In addition to the community services coordinator at each VA medical center, there is a community services coordinator at the VA Medical District level who is responsible for developing new programs, drawing up cooperative agreements between the VA and community providers, and integrating the concerns of the community services coordinator at each medical center into the District's planning process.

Some VA medical centers are part of a consortium of agencies that is unique to a specific locality. One example is the VA medical center in Tulsa, Oklahoma, that is part of the Long-Term Care Management Authority of Tulsa described in chapters 1 and 7. Another example is the VA medical centers in the Chicago area that are part of the VA/AAA Council, described in box 6-E. Like sharing agreements and

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[11] The sharing agreement described in box 6-D does not require the VA to provide direct services for nonveterans, but the VA *is* permitted to provide direct services for nonveterans in the context of a formal sharing agreement.

Box 6-D—The "Sharing Agreement" Between a VA Medical Center and an Area Agency on Aging in West Virginia

The Louis A. Johnson VA Medical Center in Clarksburg, West Virginia, has a formal (signed by both parties) sharing agreement with the area agency on aging (AAA) in nearby Fairmont, West Virginia. The agreement delineates the service coordination and case management functions the AAA is obligated to provide for veterans discharged to the community from the VA hospital and the training the VA is obligated to provide for AAA staff members and other non-VA service providers.

When a veteran is discharged to the community from the VA hospital, the Social Work Service at the VA medical center notifies the AAA. The AAA provides an assessment and, based on the results of the assessment, links the veteran to non-VA services he or she needs, such as home-delivered meals and homemaker and chore services. Since the VA medical center does not have a hospital-based home care program, the AAA also arranges for home health services, if they are needed. In return for the case management provided by the AAA, the VA furnishes training on specific topics to AAA staff and the staff of other non-VA agencies.

Through the sharing agreement, veterans who are discharged from the VA hospital are assured of receiving help in obtaining the non-VA services they need to remain at home. The AAA director believes that the formality of the sharing agreement has been important to the program's success over the years and advocates this type of agreement for all VA medical centers.

SOURCE: J. Hunter, director, Area Agency on Aging, Fairmont, West Virginia, testimony to the Joint Hearing of the Subcommittee on Hospitals and Health Care of the Committee on Veterans' Affairs and the Select Committee on Aging, House of Representatives, U.S. Congress, Washington, DC, Apr. 23, 1985; T. Moody, chief, Social Work Service, Louis A. Johnson VA Medical Center, Clarksburg, West Virginia, personal communications, Oct. 5, 1988 and July 13, 1989.

the functions of the community services coordinators, the involvement of VA medical centers in local consortiums with non-VA agencies results in greater interaction between the staff of the VA medical centers and of the non-VA agencies and thereby facilitates veterans' access to non-VA services.

Problems in Coordinating VA and Non-VA Services

According to VA officials, the major problem with the community services coordinator program is understaffing. Typically, one social worker is designated to this position in a half-time capacity and must function as the community services coordinator in addition to his or her other responsibilities (620). The primary problem with formal sharing agreements is that although the formal agreements are usually effective in coordinating VA and non-VA services, very few VA medical centers have established them. According to one VA official, the typical VA medical center has, at best, a verbal agreement with the local AAA (620).

At a 1985 joint hearing of the House Select Committee on Aging and the Veterans' Affairs Subcommittee on Hospitals and Health Care, VA officials testified that virtually all VA medical centers have established contact with AAAs, and that such contact has greatly increased the number of appropriate referrals from the VA to community agencies, and vice versa (820). A witness representing the leadership council of aging organizations testified, however, that, despite some unique local arrangements between VA medical centers and AAAs, the connections between VA medical centers and non-VA agencies in their catchment areas are generally fragmented (343).

Summary and Implications

VA hospital discharge planning and case management help link veterans to non-VA services. VA community services coordinators and formal sharing agreements and other arrangements between VA medical centers and non-VA agencies help to coordinate VA and non-VA agencies and thereby indirectly facilitate veterans' access to non-VA services. A major problem in linking veterans to non-VA services is the complexity and fragmentation of non-VA services at the community level. As discussed throughout this OTA report, a national system to link people with dementia to services would help families and others find the services they need to care for a person with dementia. One option discussed in chapter 1 is that if such a national linking system were established, VA hospital discharge planners and case managers could refer veterans with dementia to that system for assistance in locating and arranging non-VA services.

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Box 6-E—The VA/AAA Council of the Chicago Area VA Medical Centers and Three AAAs

Since 1985, the VA medical centers in the Chicago metropolitan area and three area agencies on aging (AAAs) have been working together to "provide comprehensive and coordinated social and health services to a rapidly expanding population of older veterans." Together they formed the Metropolitan Chicago Veterans Administration/Area Agency on Aging Collaboration Council—known as the VA/AAA Council.

The purposes of the VA/AAA Council are: 1) to identify areas for potential collaboration; 2) to act as an information clearinghouse and a "best practice" forum for coordinated programs and services for older veterans; 3) to facilitate joint program development, coordination, evaluation, and service delivery to older veterans; 4) to review proposed projects and make recommendations for their implementation; and 5) to help obtain funding for joint activities.

Each year the VA/AAA Council establishes priorities. This is done by sharing the agencies' specific needs and priorities for their own target populations and then identifying common areas of concern. One of the projects of the VA/AAA Council is an adult day health care program called the Alzheimer's Family Care Center. The Alzheimer's Family Care Center, which opened in 1987, is the result of collaboration between two VA/AAA Council members—the VA West Side Medical Center and the Chicago Department on Aging and Disability—and two nonmembers—Rush-Presbyterian-St. Luke's Medical Center and the Chicago Chapter of the Alzheimer's Association. The center serves both veterans and nonveterans, but veterans have priority for 40 percent of the enrollment slots.

SOURCE: "Working Together—Metro Chicago's VA and AAA—To Assist Chicago's Elderly Veterans," *Aging Network News*, May 1989, vol. 6, No. 1, pp. 3-4.

Currently, VA hospital discharge planning and case management are provided primarily for veterans who are already receiving or are eligible for VA services. As a result, some veterans who are not already receiving or eligible for VA services may not receive from the VA the help they need to find non-VA services. If a national linking system were established, that system might be given primary responsibility for helping veterans who are not already receiving or eligible for VA services to find the non-VA services they need, while the VA retained primary responsibility for helping veterans who are receiving or are eligible for VA services to find non-VA services. The other type of veterans who may not receive the help they need from the VA to find non-VA services is veterans who live far from a VA medical center. It is possible that the national linking system should also be given primary responsibility for linking those veterans to non-VA services. If, in contrast, the VA were to have primary responsibility for linking all veterans to non-VA services, it would need more staff and more resources than it now has for that purpose.

CONCLUSION

By the year 2000, there will be 9 million veterans over age 65, including two-thirds of all males over age 65 in this country. As the number of elderly veterans increases, so will the number of veterans with dementia. The VA estimates that there will be 600,000 veterans with dementia by the year 2000.

The VA operates the largest health care system in the United States and currently furnishes many of the kinds of services that may be helpful for veterans with dementia. Those services include acute medical care, diagnosis, multidimensional client assessment, nursing home and domiciliary care, hospital-based home care, adult day health care, institutional respite care, and several other programs of particular relevance for veterans with dementia and their caregivers. These services are not available at all 172 VA medical centers, however, and not all veterans with dementia are eligible for them. Moreover, some services that may be needed for veterans with dementia are not provided at all by the VA, and many VA services are furnished only on a "space available" basis, so that even if a veteran is eligible for a service and the service he needs is provided by a VA medical center that is accessible to him, he may not receive the service because the program is full.

Unless the VA were to provide all the services that may be needed for all veterans with dementia (a possibility OTA considers very unlikely), veterans with dementia are likely to need both VA and non-VA services, and effective mechanisms must be in place to link them to both. Problems of several kinds interfere with the process by which veterans

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are linked to VA services. The eligibility criteria for VA services are extremely complex. Veterans and their families do not understand the criteria and may assume the veteran is eligible for services when he or she is not, or vice versa. They also may not be aware of potentially beneficial services provided by the VA. Non-VA agencies and individual professionals and service providers who work with veterans with dementia often do not understand the VA's eligibility requirements and may not be knowledgeable about VA services. As a result, they may not be able to give veterans and their families accurate information about available services or eligibility for the services.

Other problems interfere with the process by which veterans are linked to non-VA services. Each VA medical center's Social Work Service has a community services coordinator whose job is to identify non-VA services in the community, and the VA has developed a software system to help the Social Work Service at each VA medical center maintain an up-to-date list of non-VA services. The community services coordinator position is staffed only half-time at many VA medical centers, however, and the complexity and fragmentation of non-VA services in many communities makes it difficult for anyone to maintain an accurate, comprehensive resource list.

Without effective methods for linking veterans with dementia to both VA and non-VA services, the veterans will not receive services they need, and their families are likely to be frustrated and upset. The policy question discussed in chapter 1 is the appropriate division of responsibility between the VA and a non-VA linking system for connecting veterans with dementia to services. If a national linking system were established, it could have primary responsibility for linking veterans with dementia to non-VA services. Alternatively, the VA could have primary responsibility for linking veterans to non-VA services. The pros and cons of these two alternatives are discussed in chapter 1.

As discussed earlier, the complexity of the eligibility requirements for VA services, especially as they interact with the factor of space availability mean that only the VA can finally link veterans to VA services. This report does not consider the possibility that the national linking system could perform that function. On the other hand, the linking system would have to be somewhat knowledgeable about VA services and eligibility requirements in order to know when to refer veterans with dementia and their caregivers to the VA. Finally, it is clear that the VA services are important for veterans with dementia, and the VA must be involved in the planning and operation of a national system to link people with dementia to services regardless of the specific responsibility it assumes for linking veterans with dementia to non-VA services.

Part II

Possible Approaches to Linking People With Dementia to Services

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Chapter 7

State Programs and State and Community Service Systems That Link People to Services

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Chapter 7

State Programs and State and Community Service Systems That Link People to Services

INTRODUCTION

One of the major policy issues in establishing a national system to link people with dementia to services is whether Congress should designate a single category of agencies to constitute the system nationwide or should mandate that each State designate the agencies that will make up the system in that State. In considering this issue, it is important to note that all States already have programs that link at least some people with dementia to services. In addition, some States and communities have a service system that links at least some people with dementia to services. This chapter discusses these State linking programs and State and community service systems.

As defined in this chapter, *linking programs* are programs that perform one or more of the functions that the Office of Technology Assessment (OTA) concludes are essential to a system to connect people with dementia to services:

- public education (i.e., providing programs and materials to help people understand dementia and the kinds of services that may be helpful for individuals with dementia);
- information and referral (i.e., providing information about and referrals to specific services and sources of funding for services in a community);
- outreach (i.e., using any active method to identify people with dementia and caregivers who need assistance but are unlikely to respond to public education programs or to contact an information and referral source on their own); and
- case management (i.e., assessing a client's needs, developing a plan of care, arranging and coordinating services, monitoring and evaluating services, and reassessing the client's situation as the need arises).[1]

Service systems are defined in this chapter as organizational entities that pool funds from several different sources and integrate the functions of various agencies that provide services in a given geographic area. These entities are intended to create a consolidated system through which people are connected to services. An important difference between linking programs and service systems is that linking programs can be added to the service environment in a State or locality without changing the structure, function, or relationship of existing agencies or the way services are funded, whereas the creation of a consolidated service system necessarily changes the structure, functions, and relationship of existing agencies and funding procedures.

The primary purposes of this chapter are to point out the existence of State linking programs and State and community service systems and to convey a sense of their diversity. These programs and systems are a significant aspect of the environment into which any federally mandated system to link people with dementia to services would be placed. Their existence and diversity greatly complicate the process of designing a national linking system. If States and communities did not already have linking programs and service systems, it would be relatively easy to design a national linking system. In that case, Congress could designate a single category of agencies to constitute the system nationwide without the risk of duplicating or disrupting existing State linking programs or State and community service systems. Similarly, if existing State linking programs and State and community service systems were all alike, Congress could establish a national linking system that simply connected existing programs and service systems (although in that case, such a system probably would have been established years ago).

To design a national linking system that builds on and meshes with the diverse State linking programs and State and local service systems described in this chapter is difficult. The alternative, however, is the imposition of a system that further complicates and fragments what is already an extremely complicated and fragmented service environment. For this reason, many people, including almost all the members of the advisory panel for this OTA study, believe that Congress should mandate that each State designate the agencies that will make up the linking system in that State. On the other hand, there are certain advantages to having Congress designate a single category of agencies to constitute the system nationwide, as discussed in chapter 8. The information about State linking programs and State and community service systems that is presented in this chapter is helpful in weighing these policy options.

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[1] For OTA's analysis of why these functions are essential components of a system to link people with dementia to services, see chs. 2 and 3.

The information about State linking programs and State and community service systems presented here is also relevant to another policy issue raised in the report—i.e., whether a national system to link people with dementia to services should serve only people with dementia (i.e., whether it should be dementia-specific) or whether it should serve people with other diseases and conditions as well. Most State linking programs and State and community service systems serve elderly people or elderly and disabled people. Recently, however, many States have undertaken a range of dementia-specific initiatives,[2] including dementia-specific linking programs, and a few communities have developed dementia-specific service systems.

Several State officials and other people have told OTA they are opposed to the development of dementia-specific linking programs and service systems, because, in their view, people with dementia can be served effectively by programs and systems that serve elderly and disabled people in general and because dementia-specific programs and systems contribute to the fragmentation of the service environment. On the other hand, some people, including some advocates for people with dementia and their families, believe that dementia-specific linking programs and service systems are needed because existing programs and service systems that are intended for elderly and disabled people often do not serve people with dementia effectively.

In considering the issue of whether a national linking system should be dementia-specific, it is useful to compare the dementia-specific v. general linking programs and service systems in different States and communities. In considering this issue, it is also useful to keep in mind the distinctions made in chapter 1 among the concepts *dementia-friendly*, *dementia-capable*, and *dementia-specific*. With respect to linking programs and service systems, *dementia-friendly* means that the linking program or service system is responsive to people with dementia and their caregivers. *Dementia-capable* means that the program or system is skilled in working with people with dementia and their caregivers, knowledgeable about the kinds of services that may help them, and aware of which agencies and individuals provide such services in the community. *Dementia-specific* means that the program or system serves people with dementia exclusively. As discussed in chapter 1, it is at least theoretically possible for a linking program or service system to be dementia-friendly and dementia-capable without being dementia-specific.

The information about State linking programs and State and community service systems presented in this chapter is also relevant to two other policy issues raised in the report:

1. whether agencies that constitute a national linking system should *provide* services in addition to linking their clients to services, and
2. whether the agencies that constitute the system should *allocate services or funding for services* in addition to linking their clients to services.

Some of the State linking programs and State and community service systems described in this chapter are administered by agencies that also provide services. Likewise, some of the State linking programs and all of the State and community service systems described in the chapter allocate services and/or funding for services. These State programs and State and community service systems exemplify alternate models for a national linking system.

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[2] The dementia-specific initiatives undertaken by some States and localities in the past several years include: 1) establishing task forces and commissions to study the problem of Alzheimer's disease and related disorders and recommend solutions; 2) funding biomedical research on diseases that cause dementia; 3) developing caregiver support groups and caregiver education and training programs; 4) establishing regional Alzheimer's diagnostic and assessment centers; 5) sponsoring education and training programs for service providers about Alzheimer's disease, dementia, and how to care for people with dementia; 6) establishing dementia-specific in-home, adult day, and respite services; 7) modifying the eligibility requirements for publicly funded programs so that they are available to people with dementia (e.g., by adding dementia to the categories of conditions that make people eligible for services or by lowering the age requirements for certain services so that people with dementia who are under age 60 or 65 can receive them); 8) encouraging the development of special nursing home units for people with dementia; 9) establishing guidelines or regulations for nursing home special care units; 10) establishing patient registries; 11) providing cash grants to families so that they can purchase services; and 12) prohibiting private insurance policies from excluding Alzheimer's disease as a covered condition (5,14,122,333,465,513,576).

The diversity of State linking programs and State and community service systems creates a kind of natural laboratory for comparing various approaches to linking people with dementia to services. The congressional committees that requested this assessment asked OTA to identify approaches that are being used in one State or locality and might be adapted for use in other jurisdictions. This chapter describes many such approaches.

Some of the same categories of agencies that are discussed in other chapters of this report are used by States and communities to administer their linking programs and service systems. These categories of agencies are mentioned in this chapter only if they are part of a State linking program or a State or community service system. Chapter 8 discusses area agencies on aging (AAAs), home health care agencies, community mental health centers, Alzheimer's Association chapters, the Family Survival Project, regional Alzheimer's diagnostic and assessment centers, and five other categories of agencies that link some people with dementia to services and could, at least theoretically, be designated by Congress as the basis for a national system to link people with dementia to services.

STATE LINKING PROGRAMS

Many States have linking programs that serve at least some people with dementia. The following sections describe some of these programs. The programs are categorized in terms of their emphasis on one of the four linking functions that OTA concludes are critical to an effective system to link people with dementia to services: 1) public education, 2) information and referral, 3) outreach, and 4) case management. As pointed out in the discussion, some of the programs perform more than one of these functions, but none of the programs performs all four functions. The purpose of the discussion is to convey a sense of the number and diversity of existing State linking programs and the many types of public and private agencies that are involved in implementing the programs. The discussion does not cover all State linking programs, however, and the particular programs cited are not the only good programs of their type.

Some States, notably *New York* and *California*, have numerous programs that link at least some people with dementia to services. Other States have comparatively few linking programs. The multiple linking programs in New York and California are discussed later in this chapter.

Public Education Programs

Public education programs to help people understand dementia and the kinds of services that may be helpful for individuals with dementia may be provided by various means, including pamphlets, articles, newsletters, and other publications; posters, press releases, and public service advertising in various media; radio and television programs; audiotapes and videotapes; teaching packets and curricula; lectures, community meetings, and conferences. The primary sources of public education pertaining to dementia and services for people with dementia have been the national voluntary associations that represent people with Alzheimer's disease and other diseases that cause dementia. As described below, however, some States also have developed or paid for the development of public education programs on dementia and services for people with dementia.

In *Pennsylvania*, for example, the State Department of Aging has funded a variety of public education initiatives related to dementia over the past 6 years (14,650). One of these was the production, in 1984, of a television documentary on Alzheimer's disease and related disorders entitled "You Are Not Alone." Also in 1984, the department gave a grant to the Western Pennsylvania Alzheimer's Association Chapter to develop a booklet on Alzheimer's disease, "Aging and Senile Dementia—What Every Pennsylvanian Needs To Know About Alzheimer's Disease and Other Types of Senile Dementia." The booklet has been distributed to individuals, support groups, hospitals, and other organizations. The Pennsylvania Department of Aging also developed a 4-part slide/audio training program for family caregivers of people with dementia. That program, which includes segments on community resources and financial and legal planning, is made available to caregivers through Alzheimer's Association chapters and AAAs. Still another public education activity of the Pennsylvania Department of Aging is the maintenance of a statewide clearinghouse that provides general information about dementia and the kinds of services that may be needed for people with dementia.

Like Pennsylvania, several States have dementia-specific public education programs that are administered by the State's department, division, or commission on aging. In *New Hampshire*, the State Division of Elderly and Adult Services sponsors dementia-specific public education programs that provide books, articles, videotapes, service directories, workshops, and speakers for community groups (see figure 7-1) (596). In *Kansas*, the State Department on Aging has produced and distributes comprehensive resource packets on Alzheimer's, Parkinson's, and Huntington's diseases that contain general information about the disease, appropriate treatment, community services, and sources for more information (395). The cover of each book includes a toll-free number that people can call for referrals to specific service providers (see figure 7-2). In *Delaware*, the State Division of Aging funds an Alzheimer's resource center, which provides books, audiotapes, videotapes, and other educational materials about dementia and services for people with dementia (132). In *South Carolina*, the State Commission on Aging recently produced a videotape and printed educational materials on Alzheimer's disease to train AAA staff and others who work with elderly people so that they will be able to provide public education programs in their communities (78).

Many States have established a task force or committee to study the problem of Alzheimer's and other dementing diseases, and public education has been one of the primary functions of these task forces and committees. Almost all of the task forces and committees have issued reports that provide information about dementia and services for people with dementia.[3] Members of the task forces and committees also speak about these topics to community groups. In addition, most of the task forces and committees have sponsored public meetings that serve as educational forums as well as giving family caregivers and others an opportunity to testify about the problems they face in caring for a person with dementia.

Some States, *Ohio* and *Michigan* among them, have developed or paid for the development of training manuals for family caregivers of people with dementia (528,618). Other States, including *Georgia* and *Nevada*, have funded or otherwise supported the efforts of Alzheimer's Association chapters to develop and disseminate public education materials and programs (260,576).

In *Alaska*, the Older Alaskans Commission has given grants since 1984 to the Alzheimer's Disease Family Support Group (a private organization in Anchorage) to provide statewide public education programs about dementia and services for people with dementia (282,576). Alaska has many remote communities, so the Alzheimer's Disease Family Support Group has used both teleconferences and printed materials to provide information about dementia to caregivers, providers, and others.

Information and Referral Programs

Information about and referrals to specific services and sources of funding for services in a community can be provided by telephone or in person. Most of the State information and referral programs are telephone programs. Some of the programs are intended to serve elderly people or people of all ages, and others are specifically intended to serve people with dementia.

A 1988 survey by the National Association of State Units on Aging found that 32 States had a statewide toll-free telephone information and referral program for elderly people or people of all ages: 18 of the 32 programs were for elderly people, and the remaining 14 were for people of all ages (577). The extent to which existing information and referral programs for elderly people or people of all ages meet the needs of people with dementia and their caregivers undoubtedly varies, but anecdotal reports suggest that many of the existing programs fall short in this regard. Such reports, in fact, were one impetus for this OTA study.

Some States have tried to enhance the capability of their information and referral programs to serve people with dementia by requiring special training for the staff of the programs and by developing dementia-related materials for use by the programs. In *Illinois*, for example, the Governor's Task Force on Alzheimer's Disease has developed a special information packet for people who call the State's

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[3] For a list of the reports published by State task forces and committees on Alzheimer's disease and related disorders, see app. C.

Figure 7-1—A Brochure Publicizing the Public Education and Other Services of the New Hampshire Division of Elderly and Adult Services

SERVICES OF THE NEW HAMPSHIRE DIVISION OF ELDERLY & ADULT SERVICES

Call or write the Coordinator for Alzheimer's Services at (603) 271-4687 for:

- information and referral for families
- books, articles, and videotapes on loan
- guides to services in eleven N.H. regions
- information about specific family support groups
- bibliography on ADRD
- community education speakers
- training workshops
- consultation to service programs
- respite care services

A.D.R.D.

Alzheimer's Disease & Related Disorders

New Hampshire Division of Elderly & Adult Services

A public information service of
The New Hampshire Division
Of Elderly & Adult Services
Department of Health
and Human Services
6 Hazen Drive
Concord, NH 03301
(603) 271-4687

1988

SOURCE: New Hampshire Division of Elderly and Adult Services, "A.D.R.D.," New Hampshire Department of Health and Human Services, Concord, NH, 1988.

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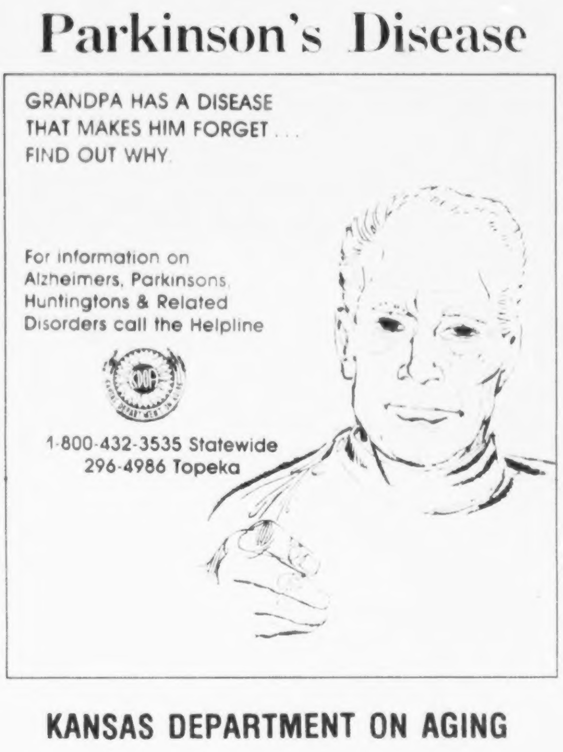
Figure 7-2—A Resource Packet on Parkinson's Disease Produced and Distributed by the Kansas Department on Aging



Parkinson's Disease

GRANDPA HAS A DISEASE
THAT MAKES HIM FORGET . . .
FIND OUT WHY.

For information on
Alzheimers, Parkinsons,
Huntingtons & Related
Disorders call the Helpline

1-800-432-3535 Statewide
296-4986 Topeka

KANSAS DEPARTMENT ON AGING

SOURCE: Kansas Department on Aging, *Resource Packet: Parkinson's Disease*, Topeka, KS, June 1988.

telephone information and referral program for seniors about services for a person with dementia (345).

As discussed below, by 1989, at least 14 States had established a statewide telephone information and referral program specifically for people with dementia. Many of the dementia-specific information and referral programs exist in addition to a State's information and referral program for elderly people or for people of all ages. In *Massachusetts*, for example, the State's Office of Elder Affairs has a statewide Alzheimer's telephone information and referral program that it has operated since 1985 (121). The State's Office of Elderly Affairs also has a separate telephone information and referral program for elderly people.

Since 1988, *Connecticut* has funded a statewide Alzheimer's telephone information and referral program through Info-Line, a United Way program (143). Before 1988, Info-Line responded to calls about services for people with dementia, but the new program provides special training about dementia and about services for people with dementia for Info-Line staff members who handle those calls.

Texas has an Alzheimer's telephone information and referral program that is operated by the State Department of Health. In 1988, the Texas Legislature mandated the development of a computerized information and referral program for people with dementia, and the Department of Health is developing that program.

Pennsylvania, New Hampshire, Kansas, and *Delaware* provide dementia-specific telephone information and referral programs through the same agencies that administer their public education programs (see previous section). *New Jersey* funds a statewide dementia-specific information and referral program through its two Alzheimer's diagnostic and assessment centers, and *Florida* funds information and referrals for people with dementia through its four memory disorders clinics.[4] *New York* and *California* also have statewide dementia-specific information and referral programs that are discussed in a later section of this chapter.

North Carolina funds a statewide telephone information and referral program for people with Alzheimer's disease and other dementias through the Duke University Medical Center's Family Support program (290). Two social workers and a secretary respond to approximately 200 calls a month and provide information about dementia, referrals to community service providers, and telephone counseling. The State-funded program also provides public education, professional and caregiver training, and caregiver support groups.

Wisconsin funds a statewide information and referral program for people with dementia and their families through the Alzheimer's Information and

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[4] New Jersey's centers and Florida's memory disorder clinics are discussed along with other State regional Alzheimer's diagnostic and assessment centers in ch. 8.

Training Center, which is operated by the Alzheimer's Association Chapter of Southeastern Wisconsin (263,410).[5] The center maintains a computerized database of all the dementia-related services in the State, organized by county. Callers, who include family caregivers and health care and social service professionals who work with dementia patients and their families, can access the information and referral program through a toll-free number. In addition to providing information and referrals, the center develops and distributes educational materials and provides training for professionals and caregivers.

The *Missouri* Division of Aging has both a statewide telephone information and referral program for elderly people and a statewide telephone information and referral program for people with Alzheimer's disease and their caregivers (219). Those programs are described in box 7-A. Anecdotal reports suggest that some caregivers of people with dementia prefer to call a dementia-specific information and referral program. Other caregivers may be reluctant to call a dementia-specific program because they are ashamed of their relative's cognitive impairment and prefer to call an information and referral program that serves elderly people in general. Still other caregivers may not consider calling a dementia-specific program because they do not think of the individual as a "person with dementia;" probably this is especially likely if the individual has physical impairments in addition to dementia. The Missouri system with its two telephone numbers, advertised separately but answered by the same staff (all of whom have received training about dementia and services for people with dementia) is a creative way of providing information and referrals for caregivers who have any of the three perspectives. The close working relationship between the State programs and the Alzheimer's Association chapters is another positive feature of the Missouri system.

In addition to maintaining telephone information and referral programs, some States have published resource directories that list available services for people with dementia. In 1988, for example, *New Jersey* published the third edition of its resource directory, *Alzheimer's Disease: A New Jersey Directory of Services for Family Caregivers and Health and Human Service Providers* (601). Some States publish directories of services for elderly people, and these directories may also be helpful for people with dementia (374).

In 1989, the Dementia Subcommittee of *Michigan's* Chronic Disease Advisory Committee proposed the establishment of a statewide network of agencies that would provide information and referrals and a variety of other services for people with dementia and their caregivers (528). One component of the subcommittee's proposal is the designation of one agency in each community as a "center for information on dementia." According to the proposal, these centers would be the focal points for information about dementia in the community. They would be the local repository for printed and audiovisual materials about dementia, lists of speakers, and other public education materials. They also "would assist families in locating and obtaining appropriate services" (528).

The Dementia Subcommittee anticipates that organizations, such as Alzheimer's Association chapters, other voluntary organizations, AAAs, local health departments, and Community Mental Health Boards will apply to be designated as centers for information on dementia (528). The subcommittee proposes that it, along with several other groups, should select one organization to be the dementia information center in each community. The selection would be based on the applying organizations' relative knowledge about dementia and services for people with dementia, their relative ability to maintain an up-to-date directory of available services, and evidence of support from other community agencies for their selection.

The working group that developed the subcommittee's proposal believed that although the centers for information on dementia would not receive any State funds, local organizations would nevertheless apply to be designated as centers because of the recognition and authority such designation would bring them (1). The subcommittee's proposal suggests that if no agency or organization applies from a particular geographic area, the State could solicit applications from agencies and organizations in that area or ask a designated center in a nearby community to expand its catchment area (528).

The working group that developed the subcommittee's proposal debated the advisability of having the local centers for information on dementia

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[5] Wisconsin's Alzheimer's Information and Training Center is described at greater length in box 8-G in ch. 8.

Box 7-A—Missouri's Information and Referral Programs for Elderly People and for People With Alzheimer's Disease

The Missouri Division of Aging has both a statewide telephone information and referral program for elderly people and a statewide telephone information and referral program for people with Alzheimer's disease and their caregivers. The information and referral program for elderly people gets about 10,000 calls a year. The Alzheimer's "Helpline" was initiated in 1988, and received 100 calls the first day. Subsequently, the number of calls decreased somewhat.

Calls to both of these Missouri information and referral programs are answered by the same staff. All staff members at these programs receive 4 to 5 hours of training by the Missouri Alzheimer's Association Coalition. The training includes an overview of Alzheimer's disease, including its causes and behavioral manifestations and its impact on family caregivers; reasons why caregivers of people with Alzheimer's disease might call the information and referral programs; the kinds of questions these caregivers might ask; potentially helpful services for people with Alzheimer's disease; and procedures for handling emergencies (e.g., the patient is lost or uncontrollably agitated or the caregiver is sick or suicidal).

When a person calls either of the Missouri information and referral programs about an individual with dementia, the program gives the person information about services and a referral to the Alzheimer's Association chapter or support group nearest the person's home (Missouri now has Alzheimer's Association chapters covering all counties in the State). The program also sends a followup letter to the Alzheimer's Association chapter to which the caller is referred unless the caller requests that no followup be made.

The general elderly and Alzheimer's-specific telephone information and referral programs of the Missouri Division of Aging both use a common computerized database of services. The database can be accessed at the Missouri Division of Aging's central office. Since it can also be accessed through computer terminals in about 100 of the division's local offices, it is available to case managers who work in those offices. The Missouri Division of Aging hopes that it will be possible in the near future to generate by computer the followup letters to Alzheimer's Association chapters about callers who have been referred to them.

SOURCES: B.L. Forbis, principal assistant to the director, Division of Aging, Missouri Department of Social Services, Jefferson City, MO, personal communications, Dec. 6, 1988, Apr. 5, 1989, and June 14, 1989; K. Higley, executive director, St. Louis Alzheimer's Association Chapter, St. Louis, MO, letter to the Office of Technology Assessment, U.S. Congress, Washington, DC, Apr. 14, 1989.

provide "gatekeeper-type" outreach[6] and case management in addition to public education and information and referral (1). Including case management and outreach as functions of the proposed centers would have made it difficult for some of the local organizations that were already providing public education and information and referrals for people with dementia and their caregivers to qualify as centers, however, and the subcommittee's final proposal did not require the centers to provide these functions (or even discuss the functions). The final proposal does recommend that the centers be able to contact service providers on behalf of dementia patients and their families, if necessary, and to follow-up to ensure that patients and families obtain needed services.

Michigan's proposed centers for information on dementia would be required to work closely with other individuals, groups, and agencies in the community, including physicians, voluntary associations, and public and private agencies that provide services for people with dementia (528). The local centers would also be required to work closely with the two other components of the proposed statewide network of agencies: regional centers and tertiary centers. According to the proposal, the regional centers would provide diagnosis, multidimensional assessment, care planning, "short-term care management," and counseling for families. The tertiary centers would provide specialized diagnostic and assessment services for dementia patients with atypical or complicated symptoms and would conduct research, education, training, and autopsy programs.

It is interesting to note that the Dementia Subcommittee's proposal places the information and referral functions in the local centers for information on dementia and places the case management functions in the regional centers (528). This is opposite to suggestions OTA has heard from other people who

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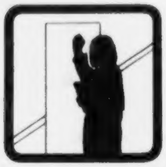
[6] The following section discusses gatekeeper programs.

believe that although information and referral can be provided effectively on a regional or statewide basis, case management must be provided by local agencies (374,595).

Outreach Programs



Outreach, as noted earlier, means using an active method to identify people with dementia and caregivers who need assistance but are unlikely to respond to public education programs or to contact an information and referral program on their own.[7] The outreach programs that most closely match the needs of isolated people with dementia and their caregivers are "gatekeeper programs" that make use of the observations of individuals who interact with many people in the course of their regular activities—e.g., utility meter readers, mail carriers, apartment managers, police, pharmacists, grocers, and delivery persons. Gatekeeper programs train such individuals to identify isolated elderly people who may need assistance and to notify a central agency. The central agency then contacts the people, evaluates their needs, and refers them to services (97,320,456,688).

The first gatekeeper program in the United States was established in 1978 by a community mental health center in Spokane, Washington.[8] Since then, gatekeeper programs have been established in many other jurisdictions, often as joint initiatives of the State department, division, or commission on aging, AAAs, and utility companies (320). Although these programs are not dementia-specific, they frequently identify and refer isolated people with dementia (97,320,456,685).

Illinois has a statewide system of gatekeeper programs that are administered by the Illinois Department on Aging and local AAAs in conjunction with several utility companies and rural cooperatives. With the addition in 1989 of Commonwealth Edison in northern Illinois, the gatekeeper programs now cover the whole State (148). The AAAs provide training for the utility workers who are the gatekeepers and determine which local agency should receive and respond to referrals from the gatekeepers. In some localities, the calls are handled by the AAA, whereas in other localities, they are handled by the case management agencies that administer Illinois' Community Care Program, a statewide long-term care program that is discussed later in this chapter.

Case Management Programs

Case management, as noted earlier, is a process that includes five core functions: 1) assessing a client's needs, 2) planning care, 3) arranging and coordinating services, 4) monitoring the services that are provided, and 5) reassessing the client's situation as the need arises.

All States have at least one program that provides case management for elderly people, although the number of people who receive case management through some of the State programs is very small (354). Some States provide case management through an independent case management program; some States provide case management as a component of a program that also allocates services or funding for services; and some States provide case management through several different programs. The number of people with dementia who receive case management through State programs is not known.

As noted in chapters 1 and 3, the implementation of case management functions varies depending on the type of agency that provides the case management, the other functions of that agency, and other factors. In State agencies that allocate services or funding for services, case management provided in conjunction with the administration of those benefits sometimes consists primarily of administrative tasks such as determining a client's eligibility for services and funding, authorizing the services and funding, and monitoring and accounting for them. Many of the case managers who work for such agencies perceive themselves not just as administrative agents but as professional helpers who assist clients in defining their service needs and locating and arranging appropriate services (47). OTA has no reason to dispute these case managers' perception that the case management they provide has both administrative and clinical/advocacy components, although case management in such agencies is undoubtedly more likely than case management provided by an independent case management program to consist primarily of administrative tasks.

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[7] As noted in chs. 1 and 3, some programs that are called "outreach" programs by the agencies that provide them—e.g., lectures given by agency staff to senior citizens or other community groups—are considered public education programs in this report.

[8] The Spokane gatekeeper program is discussed in box 8-C in ch. 8.

A 1987 survey of the 50 States and the District of Columbia conducted by the Intergovernmental Health Policy Project found that States were paying for case management for elderly people with funds from many different sources (353,354). Some States were paying for case management as an optional Medicaid benefit (allowed since 1986) or through a Medicaid 2176 waiver (both these funding sources are discussed below); 33 States were paying for case management with Older Americans Act funds; 32 States were paying for case management with State general funds; and 23 States were paying for case management with Social Service Block Grant funds.

The case management that States were paying for was administered at the State level by different agencies in different States and by several agencies in some States. These agencies include the State department, division, or office on aging, the State Medicaid agency, and the State department of health, social services, or human services (353,354). At the local level, the case management that States were paying for was provided to clients by a variety of agencies, including local offices of various State and county departments, city government agencies, AAAs, and many types of private agencies. Many States reported providing case management through several different local agencies. A few States reported contracting with individual nurses to provide case management.

As of October 1987, 15 States were paying for case management as an optional Medicaid benefit (819). OTA is not aware of any data on the number of people with dementia who receive case management that is paid for as an optional State Medicaid benefit, but some people with dementia probably do receive this benefit. To be eligible for case management as a Medicaid benefit, one must meet the State's Medicaid financial eligibility criteria, and the allowable levels of income and assets for Medicaid eligibility are low in some States and very low in other States.[9]

The Medicaid 2176 waiver program was enacted by Congress in 1981 to allow States to apply for waivers of Medicaid regulations so they could provide a coordinated package of home and community-based services for individuals who otherwise would be at risk of nursing home placement or who are already in an institution (819). A State with a Medicaid 2176 waiver:

- may use Medicaid funds to pay for services that are not ordinarily covered by Medicaid;
- may use Medicaid funds to pay for services for some Medicaid beneficiaries and not others, so that benefits can be targeted; and
- may use a higher income standard to determine individuals' eligibility for services under the 2176 waiver program than is used to determine eligibility for other Medicaid services.

As of February 1988, there were 45 Medicaid 2176 waiver programs serving elderly and disabled people in 36 States (some States had more than one such program) (819). Thirty-six of these 2176 waiver programs provided case management, and many of the waiver programs provided services that are sometimes needed for people with dementia, including homemaker services (28 programs), personal care (20 programs), adult day care (30 programs), and respite care (28 programs). In fiscal year 1986, Medicaid 2176 waiver programs across the country served a total of 78,000 elderly and disabled people (819).

Ohio's Pre-Admission Screening System Providing Options and Resources Today (PASSPORT) program has a Medicaid 2176 waiver to provide case management and an expanded package of services for people who are eligible for Medicaid-covered nursing home care but choose to remain at home (622). At the State level, the PASSPORT program is administered by the Ohio Department of Aging. At the local level, it is most often administered by AAAs. Case managers in the AAAs and other local agencies that administer the program provide an assessment and a service plan for each client, arrange the necessary services for the client, and monitor the service providers and the client on a continuing basis. The local agencies also contract with other community agencies to provide services for PASSPORT clients (623).

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[9] As of 1987, allowable monthly income levels for Medicaid eligibility ranged from $253 in North Carolina to $580 in California and $652 in Alaska. Allowable assets levels ranged from $1,500 to $1,800 (826). Some States also allow Medicaid eligibility for people who are "medically needy"—i.e., they have medical expenses that reduce their incomes to Medicaid eligibility levels. For further information on this topic, the interested reader is referred to a 1987 publication of the Congressional Research Service, prepared by the National Governors' Association, *Medicaid Eligibility for the Elderly in Need of Long-Term Care* (826).

As of September 1989, the PASSPORT program was in effect in only 12 Ohio counties and PASSPORT services were available only to people with income and assets low enough to qualify for Medicaid in Ohio. Ohio has applied to the Federal Government for a waiver to expand the PASSPORT program statewide and to make the program's services available to people with incomes up to $718 per month. People with monthly incomes above that amount would also be able to receive services through the program if they used their own income above $718 per month to pay for services (622).

Medicaid 2176 waiver programs are undoubtedly a valuable resource in linking some people with dementia to services. On the other hand, many people with dementia (like many other elderly and disabled people) are not eligible for Medicaid 2176 waiver programs because they do not meet the eligibility requirements for Medicaid-funded nursing home care (e.g., requirements with respect to their medical condition, functional impairments, and financial resources). Two 1985 studies of Medicaid 2176 waiver programs that serve elderly and disabled people found that only 5 percent of the waiver program participants had a primary diagnosis of a mental disorder—a category that included cognitive impairments and senility (131,446). It is likely, however, that Medicaid 2176 waiver programs serve some people who are demented but who do not have a primary diagnosis of a dementing disorder.

Existing Medicaid 2176 waiver programs such as the PASSPORT program in Ohio would not have the capacity to serve all people with Alzheimer's disease and other dementing disorders even if the waiver programs' eligibility criteria were changed to allow them to do so. In 1987, in commenting on Ohio's PASSPORT program, the Ohio Department on Aging noted, for example, "even if the entire caseloads of the four waiver sites were reserved for Alzheimer's patients, the available resources could respond to less than 1 percent of the need of Ohio's Alzheimer's population" (621).

Pennsylvania's Long-Term Care Assessment and Management Program (LAMP) is similar in many ways to Ohio's PASSPORT program, but it does not have a Medicaid 2176 waiver and is paid for solely with State funds (354). Pennsylvania's LAMP program offers case management and a range of services to elderly people who are eligible for Medicaid-funded nursing home care but choose to remain at home. The program is jointly administered by Pennsylvania's Departments of Aging and Public Welfare. The State of Pennsylvania contracts with local agencies to be designated as LAMP sites and to provide assessment and ongoing case management. For each client, the local LAMP agencies provide a comprehensive assessment, develop a plan of care, and arrange and monitor services. The LAMP sites contract with community agencies to provide other services. In general, the cost of services provided to LAMP clients must be less than 45 percent of the cost of nursing home care. State lottery funds are used to pay for services for LAMP clients when no other source of funding is available (505,562,651). A small study based on a probability sample of 27 people served by Pennsylvania's LAMP program in 1987 found that half had moderate or severe dementia (505).

Any local agency can be designated as a LAMP site, as long as it is capable of carrying out the required functions and is not a service provider. LAMP sites determine people's eligibility for nursing home care, so in selecting LAMP sites, Pennsylvania must evaluate whether a potential LAMP agency has any potential conflict of interest in performing that function. In 1987, all but one of the local LAMP agencies were AAAs, and in 1988, all the LAMP agencies were AAAs (652).

States With Numerous Linking Programs

Certain States, notably *New York* and *California*, have numerous State programs that link at least some people with dementia to services. The major State linking programs in New York and California are described in the following sections. The programs vary in terms of the kind of help they provide and the people they serve. Some of the linking programs in each State are dementia-specific, and others are not.

In addition to programs that are funded and administered by the State, there are many other public and private programs and agencies in each of the States that link people with dementia to services. Some of these programs are listed at the end of each section to give a sense of the large number and the different types of linking programs in the State. It should be noted that although there are some positive consequences of having numerous linking programs in the same State, a multiplicity of linking programs may not always be a good thing, since the linking programs themselves can become confusing and add to the complexity and fragmentation of the already complicated service environment.

New York State's Linking Programs

To OTA's knowledge, *New York State* has eight State programs that link at least some people with dementia to services. New York State's Department of Health administers two dementia-specific programs that link people to services:

- the *Alzheimer's Disease Community Services Program*, and
- a program of *Alzheimer's Disease Assistance Centers*.

New York's Alzheimer's Disease Community Services Program, which began in 1986, provides grants to eight Alzheimer's Association chapters to furnish public education and information and referral, in addition to training and support for caregivers of people with Alzheimer's disease and other dementias. Since 1988, the State has also funded eight Alzheimer's Disease Assistance Centers that provide diagnosis, assessment, and ongoing case management for people with Alzheimer's disease and other dementias. Seven of the Alzheimer's Disease Assistance Centers are located in medical centers of the State University of New York, and one is in a nursing home. Each Alzheimer's Disease Assistance Center has an information clearinghouse that provides information about dementia and services for people with dementia. Telephone information and referrals are not the centers' primary function, but they do respond to requests from anyone for referrals to services (608,248).

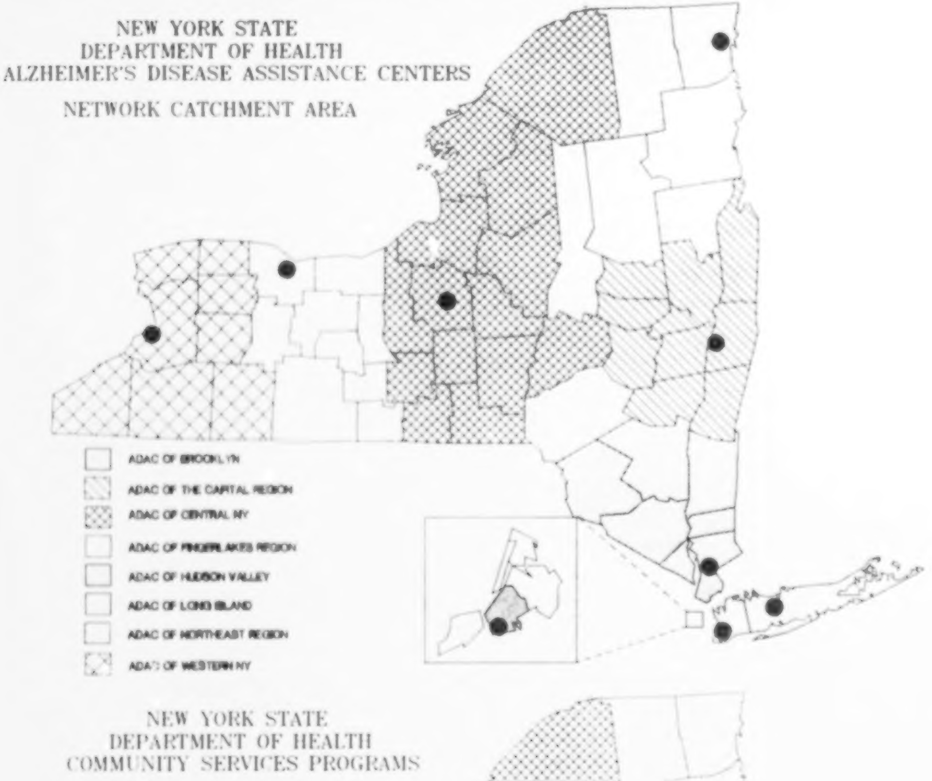
New York State's eight Alzheimer's Disease Community Services Programs and eight Alzheimer's Disease Assistance Centers are situated throughout the State (see figure 7-3), and anyone from any part of the State can use any of the programs or centers. New York State's Department of Health considers that some areas of the State are not adequately covered by the existing programs and centers, however, and plans are under way to fund additional programs and centers (248).

In addition to these two dementia-specific programs, New York also has at least six other State programs that are not dementia-specific but nevertheless link some people with dementia to services. One of the programs is the *Nursing Home Without Walls Program* (354,472). This program, begun in 1977, has had a Medicaid 2176 waiver since 1983. The Nursing Home Without Walls Program currently provides case management and in-home services for people of all ages who are sufficiently impaired to be eligible for Medicaid-funded nursing home care but choose to remain at home. At the State level, the program is administered by New York State's Department of Social Services, Division of Medical Assistance. At the local level, the program is administered by a variety of community agencies. As of 1986, the Nursing Home Without Walls program existed in 51 of New York State's 62 counties; the 95 local agencies that administered the program included home health agencies (46 percent), nursing homes (35 percent), and hospitals (19 percent). Expenditures for Nursing Home Without Walls clients are capped at 75 percent of the average annual cost of nursing home care in the State, but a 1987 State law raised the cap for people with Alzheimer's disease to 100 percent of the cost of nursing home care (354).

In addition to the Nursing Home Without Walls Program, New York State's Department of Social Services, Division of Medical Assistance, has another program that coordinates in-home and community services in order to maintain people at home who otherwise might be admitted to a nursing home. This program, the *Community Alternative Systems Agency* (CASA) program, has designated a single agency in certain communities to be the local entry point for assessment and ongoing case management for people who are eligible for Medicaid-funded in-home services. Most CASAs are county departments of social services or other county government agencies (122,354).

New York State's Medicaid program, like that in some other States, pays for case management (354). People can be eligible for Medicaid-funded case management without being so impaired that they are eligible for Medicaid-funded nursing home care, but they do have to meet Medicaid's financial eligibility criteria. As of 1987, individuals living in the community had to have an income below $432 per month to be eligible for Medicaid benefits, including case management. People with higher incomes were eligible only if their medical expenses reduced their income to the Medicaid eligibility levels (i.e., they were "medically needy").

Figure 7-3—Areas of New York Served by the State's Alzheimer's Disease Assistance Centers and Alzheimer's Disease Community Services Programs


NEW YORK STATE
DEPARTMENT OF HEALTH
ALZHEIMER'S DISEASE ASSISTANCE CENTERS
NETWORK CATCHMENT AREA
ADAC OF BROOKLYN
ADAC OF THE CAPITAL REGION
ADAC OF CENTRAL NY
ADAC OF FINGER LAKES REGION
ADAC OF HUDSON VALLEY
ADAC OF LONG ISLAND
ADAC OF NORTHEAST REGION
ADAC OF WESTERN NY
NEW YORK STATE
DEPARTMENT OF HEALTH
COMMUNITY SERVICES PROGRAMS
NETWORK CATCHMENT AREA
CAPITAL DISTRICT ADRDA
CENTRAL NY ADRDA
NYC ADRDA
PUTNAM COUNTY ADRDA
ROCHESTER ADRDA
STATEN ISLAND ADRDA
WESTCHESTER ADRDA
WESTERN NY ADRDA
CSP SUPPORTED VIA ADAC SUBCONTRACT

SOURCE: New York State Department of Health, Office of Public Health, Alzheimer's Disease and Other Dementias Program, January 1990.

New York State's Department of Social Services, Division of Adult Services, pays for case management and in-home services for adults with incomes that exceed Medicaid eligibility levels (in 1987, up to 150 percent of the poverty level). This program is funded with Federal Social Services Block Grant monies and administered at the local level by county departments of social services (354).

New York State's Office on Aging funds two statewide programs that are administered at the local level by AAAs and provide case management and other in-home and community services for people who are over age 60 and not eligible for Medicaid:

- the *Community Services for the Elderly* (CSE) program, and
- the *Expanded In-Home Services for the Elderly* (EISEP) program (354).[10]

AAAs in New York State also provide information and referrals, and some provide case management, using Federal Older Americans Act funds (354).

In addition to State linking programs, New York has many other public and private programs and agencies that link people with dementia to services. They include the New York City Alzheimer's Resource Center,[11] Alzheimer's Association chapters, community health centers, community mental health centers, hospitals, county and city government agencies, private social service and family service agencies, home health agencies, and adult day centers.

Two federally funded programs in New York State also link people with dementia to services. One is the Monroe County Long-Term Care Program in Rochester, New York, which in 1988 was designated as one of eight demonstration sites for the Medicare Alzheimer's Disease Demonstration. Like each of the other Alzheimer's demonstration sites, the Monroe County Long-Term Care Program will provide information and referrals, case management, and in-home and community services for several hundred Alzheimer's patients over a 3-year period beginning in late 1989 (504). In addition, New York State has 2 of the 15 Alzheimer's Disease Research Centers funded by the National Institute on Aging; the centers are located at Mt. Sinai School of Medicine and Columbia University, both in New York City. The centers are primarily biomedical research facilities, but they also provide educational programs for the public and information and referrals for people who are involved in their clinical research programs.

California's Linking Programs

To OTA's knowledge, *California* has seven State programs that link at least some people with dementia to services. Three of the programs serve only or primarily people with dementia. First, California's Department of Health Services funds a program of nine *Alzheimer's Disease Diagnostic and Treatment Centers* (225,335).[12] The nine centers provide diagnosis, assessment, and medical treatment for people with Alzheimer's and related dementias, conduct biomedical and clinical research on dementia, and train service providers. The centers provide educational programs for community groups and information and referrals for patients and family caregivers. One of the centers provides long-term case management. Three of the centers are located on university campuses; two are at VA medical centers; and the others are at a psychiatric hospital, a rehabilitation hospital, a community hospital, and a senior center.

Second, California's Department of Aging funds a program of *Alzheimer's Day Care Resource Centers* that provide public education, information and referrals, and professional and caregiver education and training, as well as adult day care and respite care for people with dementia (5,460,714). As of 1989, there were 26 Alzheimer's Day Care Resource Centers throughout California, administered by a variety of public and private health care and social service agencies. In 1990, 10 more centers will be added, bringing the total to 36 centers.

Third, California's Department of Mental Health funds a network of *regional resource centers for the families and caregivers of brain-impaired adults*. The centers, which are modeled after Family Survival Project in San Francisco, provide public education, information and referrals, case coordination, and other services for the families and other caregivers of brain-impaired adults, the majority of whom have dementia.[13] As of 1989, there were 11 regional resource centers (including Family Survival Project) located throughout California (see figure 7-4). Four of the centers are administered by hospitals or rehabilitation centers; others are administered by an AAA, a Catholic Charities agency, and other health care and social service agencies. Most of the centers serve several counties. Eight centers have toll-free telephone numbers, and several have family consultants who are available to people in rural parts of the centers' catchment areas (199, 200,405).

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[10] As of 1987, the EISEP program served people with incomes between 150 and 250 percent of the poverty level (354).

[11] The New York City Alzheimer's Resource Center is discussed in box 8-A in ch. 8.

[12] For additional information on California's Alzheimer's Disease Diagnostic and Treatment Centers, see the section on regional Alzheimer's diagnostic and assessment centers in ch. 8.

The State of California has designated Family Survival Project to serve not only as the Bay Area Regional Resource Center but also as the Statewide Resources Consultant. In the latter capacity, Family Survival Project maintains an information clearinghouse on dementia and other conditions that cause brain impairment and publishes a newsletter, fact sheets, brochures, directories, and research reports about services for brain-impaired adults and their caregivers (199,200,405). It also refers callers to the regional resource center designated to serve their geographic area and responds to requests for information from callers outside the State.

Since its inception as a task force of families and community leaders in 1976, Family Survival Project has lobbied, often successfully, for improved services for people with dementia, other brain-impaired adults, and their families. It maintains detailed records of services that are needed but not available to its clients. To a greater extent than any of the other agencies OTA studied in the course of this assessment, Family Survival Project uses its client records to point out to government officials and others the need for specific services. The development of California's statewide network of regional resource centers, completed in 1988, allows Family Survival Project to compile information about patients, caregivers, service use, costs, and unmet service needs for the State as a whole.

In addition to these three dementia-specific programs, California has four other State programs that are not dementia-specific but nevertheless link at least some people with dementia to services. The *Multipurpose Senior Services Program* (MSSP), which began in 1980, provides case management for elderly people who meet Medi-Cal (California's Medicaid program) eligibility requirements for nursing home care but can be maintained at home with services (101,354,534). MSSP pays for in-home and other community services for its clients if the services cannot be funded through any other source. Total expenditures for MSSP clients are capped at 95 percent of the cost of nursing home care in the State. MSSP has had a Medicaid 2176 waiver since 1983. Federal funds provided under the waiver are channeled through the State Department of Health Services to the Department of Aging which administers the program at the State level. The Federal funds are matched with State funds. As of 1987, there were 22 MSSP programs in 19 of the 58 counties of California. The programs are run by county departments of health and social services, other county and city government agencies, AAAs, hospitals, and private, nonprofit agencies.

The California Department on Aging also administers the *Linkages program*, which provides information and referrals and case management for elderly and disabled people who are at risk of nursing home placement but not eligible for nursing home care funded by Medi-Cal (California's Medicaid program). In general, Linkages clients are less impaired than MSSP clients. Linkages is funded entirely with State money, and some funds are available to purchase in-home and other community services for Linkages clients (101,354).

As of 1987, there were 13 Linkages programs in California. At the local level, the 13 programs were administered by a variety of public and private agencies: the City of Oakland Social Services Department; Community Care Management Corp. in Ukiah; Humbolt Senior Citizens Council in Eureka; Senior Care Action Network in Long Beach; Huntington Memorial Hospital in Pasadena; Altamed Health Services Corp. in Los Angeles; Mt. Zion Hospital and Medical Center in San Francisco; San Mateo County Department of Health Services; the San Diego County AAA; San Joaquin Department of Aging, Children's, and Community Services; Jewish Family Services of Los Angeles; Monterey County Department of Social Services; and Westside Center for Independent Living in West

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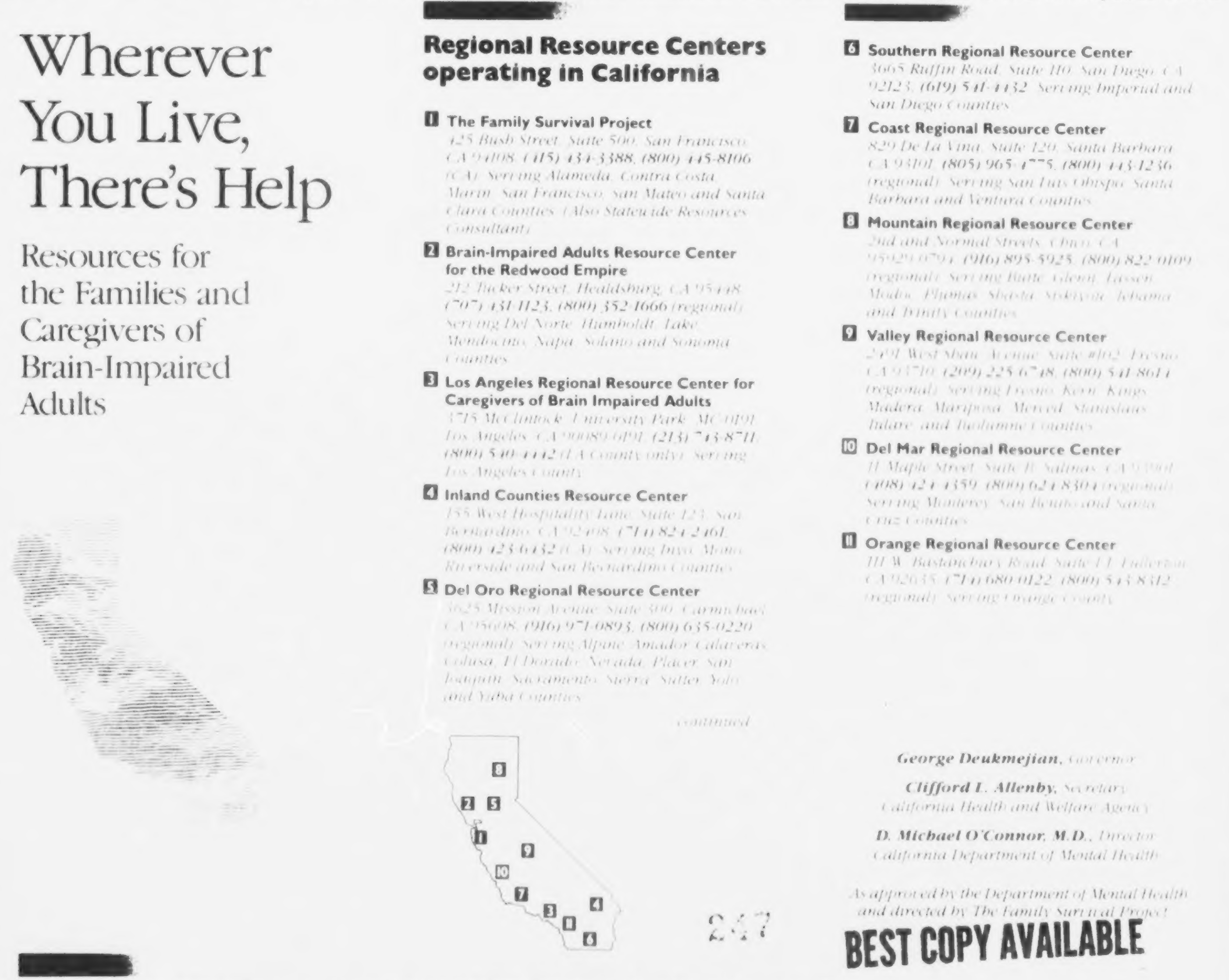
[13] For more information about Family Survival Project and California's regional resource centers, see the discussion of Family Survival Project in ch. 8.

Figure 7-4—A Brochure Publicizing California's 11 Regional Resource Centers for the Families and Caregivers of Brain-Impaired Adults



Wherever You Live, There's Help

Resources for the Families and Caregivers of Brain-Impaired Adults

Regional Resource Centers operating in California

1 The Family Survival Project
425 Bush Street, Suite 500, San Francisco, CA 94108. (415) 434-3388, (800) 445-8106 (CA). Serving Alameda, Contra Costa, Marin, San Francisco, San Mateo and Santa Clara Counties. (Also Statewide Resources Consultant)

2 Brain-Impaired Adults Resource Center for the Redwood Empire
212 Tucker Street, Healdsburg, CA 95448. (707) 431-1123, (800) 352-1666 (regional). Serving Del Norte, Humboldt, Lake, Mendocino, Napa, Solano and Sonoma Counties

3 Los Angeles Regional Resource Center for Caregivers of Brain Impaired Adults
3715 McClintock, University Park, MC-0191, Los Angeles, CA 90089-0191. (213) 743-8711, (800) 540-4442 (LA County only). Serving Los Angeles County

4 Inland Counties Resource Center
155 West Hospitality Lane, Suite 123, San Bernardino, CA 92408. (714) 824-2461, (800) 423-6432 (CA). Serving Inyo, Mono, Riverside and San Bernardino Counties

5 Del Oro Regional Resource Center
3625 Mission Avenue, Suite 300, Carmichael, CA 95608. (916) 971-0893, (800) 635-0220 (regional). Serving Alpine, Amador, Calaveras, Colusa, El Dorado, Nevada, Placer, San Joaquin, Sacramento, Sierra, Sutter, Yolo and Yuba Counties

continued

6 Southern Regional Resource Center
3665 Ruffin Road, Suite 110, San Diego, CA 92123. (619) 541-4432. Serving Imperial and San Diego Counties

7 Coast Regional Resource Center
829 De La Vina, Suite 120, Santa Barbara, CA 93101. (805) 965-4775, (800) 443-1236 (regional). Serving San Luis Obispo, Santa Barbara and Ventura Counties

8 Mountain Regional Resource Center
2nd and Normal Streets, Chico, CA 95929-0794. (916) 895-5925, (800) 822-0109 (regional). Serving Butte, Glenn, Lassen, Modoc, Plumas, Shasta, Siskiyou, Tehama and Trinity Counties

9 Valley Regional Resource Center
2491 West Shaw Avenue, Suite #102, Fresno, CA 93710. (209) 225-6748, (800) 541-8614 (regional). Serving Fresno, Kern, Kings, Madera, Mariposa, Merced, Stanislaus, Tulare and Tuolumne Counties

10 Del Mar Regional Resource Center
11 Maple Street, Suite B, Salinas, CA 93901. (408) 424-4359, (800) 624-8304 (regional). Serving Monterey, San Benito and Santa Cruz Counties

11 Orange Regional Resource Center
111 W. Bastanchury Road, Suite 1J, Fullerton, CA 92635. (714) 680-0122, (800) 543-8312 (regional). Serving Orange County

George Deukmejian, *Governor*

Clifford L. Allenby, *Secretary*
California Health and Welfare Agency

D. Michael O'Connor, M.D., *Director*
California Department of Mental Health

As approved by the Department of Mental Health and directed by The Family Survival Project

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Los Angeles. All but the last two agencies also run MSSP programs (101).[14]

Another program of California's Department on Aging, the *SEED Community Long-Term Care Project*[15] does not directly link individuals to services; instead, the SEED program encourages coordination of long-term care services in local communities, primarily through the development of integrated screening and intake procedures and the use of a uniform assessment instrument by different agencies that provide services (101,354,714). In 1986, the State Department on Aging designated 11 SEED communities. The SEED lead agency in most of the 11 communities was the AAA, but in 2 communities, it was the county department of social services and in 1, the county department of health services. Of the 11 SEED communities, 9 have an MSSP program, and 7 have a Linkages program, but these MSSP and Linkages programs are not necessarily administered by the SEED lead agency. In some SEED communities, the program has served as a catalyst for the coordination of programs of the California Department on Aging (e.g., MSSP and Linkages) and the involvement of agencies that administer programs of the State Departments of Social Services and Mental Health, and other agencies.

The California Department on Aging also funds a program of *Community-based Respite Care Services* in eight areas of the State. The local agencies that administer this program recruit and train respite care workers and provide information about and referrals to respite care for adults with chronic physical or mental impairments. Although the program is not dementia-specific, people with dementia and their caregivers are among its primary clients (460). The local agencies that administer the program include two AAAs, a hospital, a community health center, two senior citizens agencies, and two agencies that serve disabled people.

Finally, the California Department of Social Services administers the *In-Home Supportive Services* (IHSS) program, which provides case management and in-home personal care and chore services for people of all ages with monthly income of $726 to $1,051 (depending on their degree of functional impairment). The program is funded with Federal Social Services Block Grant monies and other State funds. It is administered at the local level by county departments of social services (354).

In the early 1980s, an attempt was made to consolidate long-term care services for elderly and disabled people in California under a single State department. In 1982, the California Legislature passed a bill (AB 2860) to create a State Department of Aging and Long-Term Care and to authorize the new department to pool funds from various sources to provide services for elderly and disabled people. The 1982 bill created a task force to make recommendations to the governor and the legislature pertaining to the implementation of its provisions. In the following year, however, agreements and compromises that had been worked out previously among the interest groups that had supported the bill broke down. The greatest disagreement occurred between aging and disability interest groups, each of which feared that implementation of the bill might reduce overall funding for services for its constituents. Because of the disagreement, the California Legislature passed a substitute bill (AB 2226) in 1984. The new bill created a Division of Long-Term Care in California's Department on Aging and assigned that department primary responsibility for developing a long-term care system, but it abandoned—at least temporarily—the goal of consolidating all long-term care services into a single State department. Instead, the bill authorized several initiatives to coordinate services at the community level (362,746). The Linkages and SEED programs described earlier were two of those initiatives (101,714).

In addition to State-funded and/or State-administered linking programs, California has many public and private agencies that link people with dementia to services. They include Alzheimer's Association chapters and other voluntary organizations that represent people with dementia and their caregivers; community mental health centers; community health centers; local government agencies; hospitals; private social service, family service, and home health agencies; and adult day centers. California also has 2 of the 15 Alzheimer's Disease Research Centers funded by the National Institute on Aging; they are located at the University of California in San Diego, and the University of Southern California in Los Angeles. As noted in the discussion of New York's linking programs, Alzheimer's Disease Research Centers are primarily biomedical research facilities, but they also provide educational programs about dementia for the public and information and referrals for people who are involved in their clinical research programs.

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[14] Altamed Health Services, a community health center in Los Angeles that operates an MSSP program and a Linkages program, is described in box 8-E of ch. 8.

[15] When this program was first envisioned, SEED was selected as an acronym to describe the "service-enriched" areas that were to be the focus of the program. The Department continued to use the name SEED when the approach was broadened to include communities with only modest or moderate resource levels (714).

Summary and Implications for a National System to Link People With Dementia to Services

Many States have linking programs—i.e., public education, information and referral, outreach, and case management programs—that serve at least some people with dementia. The programs are diverse, but some generalizations can be made:

- Some States have dementia-specific information and referral programs (sometimes in addition to the State's information and referral programs for elderly people or people of all ages). State outreach and case management programs generally are not dementia-specific, however. (Public education about dementia and services for people with dementia is, by definition, dementia-specific.)
- Dementia-specific State programs tend to be new, whereas many of the programs intended to serve elderly and disabled people in general have been in existence longer.
- Many, although certainly not all, of the dementia-specific programs (primarily public education and information and referral programs) are programs of State departments, divisions, or commissions on aging. In contrast, case management programs, which generally are not dementia-specific, are administered and/or funded by a variety of State agencies.
- In many States, public education and information and referral are provided through the same program, but active outreach and case management are provided through other programs. Thus, the four functions identified by this OTA assessment as essential components of an effective linking system for people with dementia are not provided through the same program.

Despite these generalizations, the main conclusion to be drawn from the preceding section is the diversity of existing State linking programs. They vary in terms of the State agencies that administer and/or fund them, the local agencies that implement them, the linking functions and other services they provide, and the people they serve.

As noted at the beginning of this chapter, the diversity of existing State linking programs makes it difficult to design a national linking system that would build on rather than duplicate or disrupt the programs. Clearly, there is no single type of State agency that administers most of the existing programs and is therefore the obvious choice to administer a national linking system. State aging agencies (departments, divisions, commissions, etc.) probably administer more of the existing linking programs than any other type of State agency, but many other types of State agencies also administer these programs. Moreover, in many States, several State agencies administer linking programs. Each of the State agencies that administers a linking program has a constituency of clients that benefit from its program and of agencies and individuals that implement the program at the community level, all of whom have a stake in the continuation of the existing program. If Congress mandated a single category of agencies to constitute a national linking system, that decision would undoubtedly engender resistance from the State agencies that administer existing linking programs. Likewise, such a decision would engender resistance from the agencies and individuals that implement the existing State linking programs at the community level but were not chosen to implement the national system.

The preceding discussion of State programs that link people to services focused attention on the States that have such programs. The number of States that provide and/or fund public education, information and referral, outreach, and case management programs that serve at least some people with dementia is impressive and is growing. On the other hand, it is also true that some States do not have programs that link people with dementia to services or have programs that only serve a small percentage of all people with dementia and their caregivers. All States have case management programs, for example, but many of the programs serve only people with very low income and people who are so ill or functionally impaired that they are eligible for Medicaid-funded nursing home care. Therefore, although many States have linking programs that serve at least some people with dementia, many people with dementia still are not served. In addition, since the four functions identified by this assessment as essential components of an effective linking system for people with dementia are not provided through the same program, some people with dementia and their caregivers "fall through the cracks" between programs.

STATE AND COMMUNITY SERVICE SYSTEMS

In addition to, or instead of, establishing public education, information and referral, outreach, and case management programs that are added to the existing service environment, some States and communities have made fundamental changes in the existing service environment by coordinating agencies' functions and pooling funding sources to create a consolidated service system. These systems, through which people are connected to services, are often referred to as "long-term care systems." They generally connect their clients to a range of services, including many of the health care, long-term care, social, and other services that may be needed for a person with dementia.

Several topics related to State and community consolidated service systems are addressed in the following sections. The first topic considered is why some States and communities have created consolidated service systems. The second is what types of changes are involved in developing such systems. Also discussed below are the consolidated long-term care service systems in three States (Oregon, Wisconsin, and Illinois) and four communities. The concluding section of the chapter discusses some findings of long-term care demonstration projects that have influenced the development of State and community service systems.

Each of these topics could be the subject of a full report. OTA's objective here is only to provide a brief overview of State and community service systems in order to point out some of the ways in which such systems differ from the linking programs described in the previous section of this chapter and to consider the current and potential role of such systems in linking people with dementia to services. For more information on State long-term care service systems, the interested reader is referred to the following publications:

- *Building Affordable Long-Term Care Alternatives: Integrating State Policy*, published by the National Governors' Association (586).
- *State Long-Term Care Reform: Development of Community Care Systems in Six States*, published by the National Governors' Association (587).
- *State Financing of Long-Term Care Services for the Elderly*, published by the Intergovernmental Health Policy Project (353,354).

OTA's analysis below draws heavily from these publications.

Why Some States and Communities Have Developed Consolidated Long-Term Care Service Systems

The States and communities that have developed consolidated long-term care service systems have done so for several interrelated reasons. One reason is to reduce the complexity and fragmentation of the service environment so that people can connect to the services they need (353,362,587). The extreme complexity of the service environment in many communities was discussed in chapters 1 and 2. Health care, long-term care, social, and other services may be provided by many different agencies and individuals. Likewise, there are many potential sources of funding for services. Each service provider and funding source has complex rules that restrict what services are provided or paid for and who can receive them. Often, an individual's service needs cannot be met by a single agency, so the person must either interact with several different agencies or forgo needed services. By coordinating agencies' functions and pooling funding sources, some States and communities hope to make it easier for people to connect to appropriate services.

A second reason why some States and communities have developed consolidated long-term care service systems is to limit unnecessary use of nursing home care. In 1986, public spending for nursing home care amounted to $18.1 billion—87 percent ($15.8 billion) of which was from Medicaid (828). Because of the growth in the size of the elderly population—particularly growth in the age group over 85, which is most at risk of nursing home placement—there has been, and continues to be, concern that nursing home use will increase greatly and that Medicaid expenditures for nursing home care will rise accordingly (362,372). To address that problem, States have instituted a variety of measures. Many States have certificate-of-need programs to limit the creation of new nursing home beds. Many States have also initiated nursing home preadmission screening programs to evaluate nursing home applicants and divert those who can be cared for at home (666). In addition, some States and communities have developed consolidated service systems to facilitate the targeting of services to people at risk of nursing home placement, thereby enabling them to remain in their homes (362,372).

A third reason why some States and communities have developed consolidated long-term care service systems is to create an organizational and administrative structure that allows for efficient and appropriate use of limited services and funds:

- by targeting available services to the people who need them most, especially those at risk of nursing home placement;
- by avoiding duplication of local agencies' efforts, particularly repeated assessments of the same person by each agency that provides services for the person; and
- by increasing administrative control and accountability for the use of public funds.

A major objective of the States that have developed consolidated long-term care service systems is to shift some of the public funds now spent on nursing home care to in-home and community services (353,362,374,587). (As of 1987, more than 80 percent of Federal and State spending for long-term care for elderly people went for nursing home care, leaving less than 20 percent for in-home and other community services (353).)

None of the reasons and objectives just cited are incompatible with the goal of linking at least some people with dementia to appropriate services. The fact that some State and community service systems focus on limiting the use of nursing home care and targeting services to people who are eligible for or at risk of nursing home placement means, however, that the linking functions performed by these systems often are not available to people who are not eligible for or at risk of institutionalization—including many people with dementia.

Changes Involved in Developing a Consolidated Service System

The development of a consolidated service system may involve several different kinds of changes in agencies and procedures at the State and community level, including:

- the designation of a single State agency to administer all the Federal and State programs that pay for services;
- the designation of a single agency at the community level to administer services paid for by all Federal, State, and local government programs;
- the pooling of funds from different programs to pay for services; and
- the establishment of a uniform client assessment procedure, including the use of a common assessment instrument, for services paid for by various programs.

Historically, each State has established agencies to administer health care, mental health, social service, public assistance, and other programs. Typically, the structure and functions of existing State agencies has been adjusted to incorporate new Federal and State programs enacted over the years. For each new Federal or State program that has been established, some States have created a new State agency; some have created a new division in an existing State agency; and some have expanded the functions of an existing State agency. The creation of new State agencies or divisions to administer new Federal programs has been fostered by the distinct and often inflexible rules and regulations that have accompanied each new Federal program (353).

In 1987, the Intergovernmental Health Policy Project surveyed the 50 States and the District of Columbia to determine how they were financing and administering services for elderly people (353). The survey gathered information about State agencies that administer Medicaid, Medicaid 2176 waiver programs, the Older Americans Act, the Social Services Block Grant, State supplemental payments to elderly people receiving Federal Supplemental Security Income payments, and State general funds that pay for services for elderly people. The 1987 survey found that:

- 1 State (Oregon) was using the same agency to administer all the Federal and State-funded programs and services that were studied,

- 19 States were using 2 State agencies or divisions to administer the programs and services,
- 24 States were using 3 agencies or divisions to administer the programs and services, and
- 7 States were using 4 agencies or divisions to administer the programs and services (354).

The 1986 survey did not ask about State agencies that administer mental health services or services for nonelderly disabled adults. In some States, those services, which may benefit people with dementia, are administered by still other State agencies.

The designation of a single State agency to administer all the Federal and State programs that pay for services for elderly and disabled people requires a State to overcome substantial barriers—barriers created by the inflexible rules and regulations of each Federal program, barriers created by organizational and turf issues that cause resistance to change in existing State agencies, and barriers created by concerns of various interest groups that the consolidation of programs and funding sources at the State level will reduce overall funding for the client population they represent. For these and other reasons, States that have developed consolidated service systems have moved slowly in merging administrative authority for different programs at the State level, and some of those States have instead created an umbrella State agency or an interagency coordinating group to oversee the different State agencies that administer the programs (587).

The other three kinds of changes that may be involved in creating a consolidated service system—the designation of a single agency at the community level to administer services funded by all Federal, State, and local programs, the pooling of funds from different programs to pay for services, and the establishment of a uniform client assessment procedure—also require overcoming barriers created by inflexible program rules and regulations, by organizational and turf issues that cause resistance to change, and by interest group concerns. States and communities that have developed consolidated service systems generally have moved slowly and incrementally in implementing these changes.

Three other mechanisms are frequently part of consolidated service systems, but, unlike the four kinds of changes already discussed, these three mechanisms can be implemented by a single agency in a State or community without changing the structure or functions of other agencies. The three mechanisms are:

- case management,
- nursing home preadmission screening, and
- contracts with service providers.

All State and community consolidated service systems include case management as a major component. In fact, consolidated service systems are sometimes referred to as "case-managed systems." The role of the case manager in such systems is often quite different from the traditional case management role in which the case manager coordinates or "brokers" services from various community agencies for an individual client; in a consolidated service system, a case manager more often administers and allocates services that are already coordinated by the structure and functions of the system. Many analysts have noted the distinction between the coordination or brokering of services for an individual client from various community agencies and coordination of services through a service system (see, e.g., Austin et al. (47), Kodner and Feldman (423), and Zawadski (939)). That distinction is not always recognized, however, and some people wrongly assume that case management by itself creates a consolidated service system.

State consolidated service systems generally include nursing home preadmission screening programs as a component. As of 1986, 29 States and the District of Columbia had nursing home preadmission screening programs; in addition, some States had programs to coordinate or fund in-home and community services for people whom the preadmission screening program found ineligible for nursing home care (356). In 1987, a Federal law was enacted that required States to establish a nursing home preadmission screening program to identify mentally ill and mentally retarded people for whom nursing home placement is inappropriate (Public Law 100-203). OTA does not know how the preadmission screening programs that are developed in response to the 1987 law will function with respect to preadmission screening programs that predated the law; nor does OTA know how many of the new programs coordinate, provide, or fund in-home and community services for people who are ineligible for nursing home care. Clearly, however, not all nursing home preadmission screening programs are part of a consolidated service system, and by themselves, nursing home preadmission screening programs do not create a consolidated service system.

Lastly, most State and community consolidated service systems contract with agencies and individuals to furnish services to their clients. Some agencies that are not part of a consolidated service system also contract with other agencies to provide services for their clients. Although an agency's contracts with other service providers undoubtedly facilitate access to care for the agency's clients, contracts for services do not by themselves create a consolidated service system.

Three States' Consolidated Service Systems

Oregon, Wisconsin, and Illinois are three States that have gone farther than most in creating consolidated service systems through which people are connected to services. Their service systems are described briefly below. The emphasis in the discussion is on the changes that were made to develop each system and the difficult organizational and turf issues that had to be addressed in the process.

Oregon's Consolidated Long-Term Care Service System

In Oregon, all publicly funded long-term care services for elderly and disabled people are administered by a single agency at the State level—the Division of Senior Services—and a single local agency in most communities (433). The Division of Senior Services and the local agencies administer Medicaid, a large Medicaid 2176 waiver program, Older Americans Act funds, Social Services Block Grant funds, and Oregon Project Independence, a State-funded program that provides in-home and community services for people over age 60.

The development of Oregon's consolidated service system began in the mid-1970s as a result of the State's concern about increasing nursing home costs (434). In 1975, Oregon Project Independence was established by the State with the objective of substituting in-home and community services for nursing home care. In 1980, Oregon initiated a nursing home preadmission screening program and a long-term care demonstration project that paid for expanded in-home and community services in four counties; the main focus of Oregon Project Independence was coordination of the various agencies that provided and paid for services—"getting everybody to talk the same language and plan the same actions" (434).

Late in 1980, the Oregon Department of Human Resources developed a proposal to consolidate the administration of aging and long-term care services in a single State agency. The proposal was rejected by other State and local agencies and by advocates for the elderly because they had not been involved in the planning process. Following the proposal's rejection, the governor appointed a planning committee that met weekly for several months and involved more than 100 people in its planning process. The planning committee's work and deliberations by the Oregon Legislature resulted in a 1981 law that created Oregon's Division of Senior Services by merging the functions of the State aging agency and the long-term care division of the State Medicaid agency. Each AAA in Oregon that was part of local government (i.e., counties or councils of government) was given the option of becoming the single agency to administer all publicly funded services for elderly and disabled people at the local level. Under the 1981 law, AAAs that were private nonprofit organizations were allowed to administer Older Americans Act and Oregon Project Independence services, but a district office of the Senior Services Division still had to perform Medicaid-related functions, including nursing home preadmission screening. Most AAAs that were given the option of administering all the services chose to do so. As of 1987, 11 of the Oregon's 18 AAAs were administering all publicly funded services for elderly and disabled people (434,587).

When the State law creating the Division of Senior Services passed in 1981, Oregon applied for a Medicaid 2176 waiver to increase the availability of in-home and community services. Oregon's waiver proposal, which was based on the four-county demonstration project begun the previous year, was approved by the Federal Government in less than a month (434).

The implementation of all these changes led to significant tension and disagreements among the State agencies, AAAs, service providers, and aging and disability advocacy groups in Oregon. In 1984, the State took the unusual step of hiring a consultant to conduct a formal negotiating process. That process, in which representatives of each group met for 1 day every other week for over 6 months, eventually resolved most of the major areas of disagreement (434,587).

By combining Federal and State funds from various programs, the State of Oregon can provide case management and in-home and community services to many elderly and disabled people. Still, Oregon's long-term care system does not serve every person who needs help. Services generally are targeted to people who are severely functionally impaired and people with low incomes, although some services are not means-tested or are provided on a sliding-fee-scale basis to people with higher incomes. Since 1983, the State of Oregon has provided case management for some elderly and disabled people who are not otherwise eligible for services due to their income or level of impairment (434,587). As of July 1989, Oregon had allocated funds for in-home and community services for some people with Alzheimer's and related dementias who are under age 60 and have not been eligible for services previously (436).

Wisconsin's Consolidated Long-Term Care Service System

In Wisconsin, publicly funded long-term care services are administered at the State level by three units of the Wisconsin Department of Health and Social Services: the Division of Health, which administers Medicaid, and two bureaus of the Division of Community Services, which administer all other programs that provide in-home and community services (354,587). The coordination of these services occurs primarily at the county level. County government agencies administer Medicaid, Social Services Block Grant funds, and several small Medicaid 2176 waiver programs, as well as the Community Options Program, a State-funded program described below. The State of Wisconsin has six AAAs that are administratively separate from county government but allocate Older Americans Act funds to county government aging units.

In 1976, the Wisconsin Lieutenant Governor's office initiated demonstration projects in four counties to substitute in-home care for nursing home care. Although the demonstration projects were considered unsuccessful by some people, in part because they were not administered by county government, they did create experience and knowledge about how to provide community care (587).

In the late 1970s, Wisconsin had a very high ratio of nursing home beds to elderly residents as compared to the ratio in other States, and Medicaid spending for nursing home care was increasing rapidly. To address that problem, the State convened people from State and local agencies, researchers, advocates, and nursing home administrators. According to one observer, the meetings resulted in "organizational fratricide and conceptual chaos:"

> Within minutes, these official planning sessions evolved into the great ritual debates of long-term care policy. Health care providers and social service agencies quickly were accusing each other of failing to integrate. The partisans of a particular functional assessment tool rushed to ridicule the conceptual flaws and inaccuracies of everybody else's preferred tool . . . The administrators of means-tested programs belittled the lack of targeting of non-means-tested programs. In one corner there was a centralization v. decentralization debate. And everybody who was not involved in the conceptual controversies was whispering to each other the real question, Who is going to get the contracts? (594).

Having failed with this approach, the State of Wisconsin tried instead asking consumers of long-term care services—elderly and physically disabled people and families of developmentally disabled people—what kinds of services and programs they needed (594). State officials believe the system finally put in place in Wisconsin reflects these consumers' preferences.

In 1981, the Wisconsin Legislature enacted a moratorium on nursing home bed expansion. At the same time, it established the Community Options Program. The Community Options Program is a State-funded program that provides case management and in-home and community services for elderly, physically disabled, developmentally disabled, chronically mentally ill, and chemically dependent people, including both children and adults. It began in eight counties in 1982 and was extended to the whole State by 1986. The Community Options Program makes State funds available to counties to provide case management and services for people who are assessed as requiring nursing home care. The State of Wisconsin does not specify what services shall be covered, encouraging complete flexibility in meeting individual needs, but per person expenditures averaged across a county's caseload cannot exceed the State's share of the cost of nursing home care for an individual (354,587).

Counties in Wisconsin can administer the Community Options Program through the county social services department (which administers other programs for elderly and physically disabled people) or through a "county 51 board" (which administers programs for mentally ill, developmentally disabled, and chemically dependent people).[16] As of 1987, 80 percent of counties in the State were using a county social services department to administer the Community Options Program, and 20 percent were using a "county 51 board." The State of Wisconsin does not require that counties use a uniform client assessment procedure, but there is a recommended assessment instrument (587).

Like Oregon's system, Wisconsin's long-term care service system targets services to people who are severely functionally impaired and people with low income (354,587). Services are provided free to individuals with income below a given threshold and on a sliding-fee-scale basis to individuals with incomes above the threshold. Assessment and care planning are provided to anyone who may need long-term care, without regard for the person's income.

In 1986, the State of Wisconsin extended eligibility for case management and services through the Community Options Program to people in the early and middle stages of Alzheimer's disease who are not yet severely functionally impaired. In addition, the State provides grants of up to $4,000 a year for families who are caring for a person with dementia, as long as the income of the individual and his or her spouse is $40,000 or less. In some cases, the grant funds are given directly to the families, but more often they are used to purchase services for them. Overall funding for the grant program is capped, however, so not all families who are eligible actually receive grants (587,918). As noted earlier in this chapter, Wisconsin also funds the Alzheimer's Information and Training Center, which is operated by the Southeastern Wisconsin Alzheimer's Association Chapter.

Illinois' Consolidated Long-Term Care Service System

In Illinois, publicly funded long-term care services are administered at the State level by three State agencies. Long-term care services for elderly people are administered by the Illinois Department of Public Aid (which administers Medicaid) and the Illinois Department of Aging (which administers Older Americans Act funds and Illinois' Community Care Program, which provides case management and three services—homemaker, adult day, and chore services—for people over age 60 who are eligible for nursing home care). Services for disabled people under age 60 are administered by the Illinois Department of Rehabilitation. At the State level, the coordination of services administered by these three agencies occurs through an interagency coordinating group. At the local level, coordination occurs through "case coordination units"—public and private agencies designated by the State to implement the State's Community Care Program (587).

The development of Illinois' long-term care service system began in 1977 with the initiation of pilot programs that provided in-home services in three areas of the State and the passage of a bill to provide certain in-home and adult day services on a statewide basis. At first, the services were administered by the Illinois Department of Public Aid. Because aging advocacy groups objected to the "welfare stigma" associated with that department, however, administrative responsibility for the services was shifted in 1979 to the Illinois Department on Aging. This department allocated funds for services to the State's 13 AAAs; and the AAAs, in turn, provided case management and purchased services for eligible clients. That arrangement lasted 1 year and was then replaced by a system in which the State of Illinois contracted directly with community agencies to provide both case management and services for eligible people (587)

Over time, waiting lists developed for services provided by Illinois' Community Care Program (587). In 1982, a class action suit filed on behalf of people on the waiting lists resulted in a court decision that prohibited waiting lists for the program, in effect making it an entitlement program. To control the overall cost of the Community Care Program, the State of Illinois instituted sliding-scale fees for services. The State also obtained more funds for the program through a Medicaid 2176 waiver. Lastly, the functions of case management and service provision were separated to avoid the possibility that case managers who worked for agencies that provided services would authorize more of their agencies' services than clients needed. The State of Illinois contracted directly with some community agencies to be "case coordination units" to provide client assessments, care planning, and ongoing case management, and the State contracted with other agencies to provide services. Case coordination units are not allowed to provide services for Illinois' Community Care Program.

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[16] "County 51 boards" are local boards designated under Chapter 51 of Wisconsin's statutes to administer community mental health, developmental disabilities, alcoholism, and drug abuse programs.

As of 1987, one-third of Illinois' 63 case coordination units were home health agencies; another one-third were senior service agencies; and the remainder were health care, mental health, family service, and social service agencies. All the case coordination units use a common client assessment instrument. They do preadmission screening, but they do not determine financial eligibility for Medicaid, a function performed by local offices of the Illinois Department of Public Aid (587).

Like Oregon's and Wisconsin's systems, Illinois' consolidated service system targets long-term care services to people who are severely functionally impaired and to people with low incomes. To be eligible for services through Illinois' Community Care Program, individuals must have less than $10,000 in liquid assets. Individuals whose monthly income is below the Medicaid eligibility level receive services without any charge. Those whose monthly incomes exceed that level must pay a fee based on a sliding scale. The case coordination units receive Older Americans Act funds to provide assessments and care planning for people who are not eligible for the Community Care program (587). Case managers who work for the case coordination units receive special training about Alzheimer's and other dementias (345).

Four Communities' Service Systems

Some communities have developed or are developing service systems to rationalize the local service environment, reduce duplication of efforts by agencies that deal with the same client, and help people connect to appropriate services. The following sections describe four such systems:

- in Tulsa, Oklahoma;
- in Linn County, Iowa;
- in three counties in northern New Hampshire; and
- in four counties in northwestern Ohio.

The systems described differ in ways that reflect the characteristics and needs of the communities they serve and the types of agencies already in place in those communities. Two of the systems (the ones in Tulsa, Oklahoma, and Linn County, Iowa) serve elderly people in general, and two (those in northern New Hampshire and northwestern Ohio) are dementia-specific. Each of the four systems was developed and is operated by a consortium of public and private agencies.

Tulsa's Long-Term Care Management Authority (Oklahoma)

In 1987, Tulsa, Oklahoma, established the Nation's first public long-term care management authority (557). Six agencies participated in its establishment:

1. the local AAA,
2. the State Medicaid agency,
3. the Veterans Administration (VA),
4. the city of Tulsa,
5. the county of Tulsa, and
6. the United Way.

Tulsa's Long-Term Care Management Authority was built on the success of an earlier effort to coordinate home care services by a consortium of local agencies (557). In 1983, five public and private agencies that were funding home health aide, homemaker, companion, and chore services in Tulsa agreed to establish a joint process to contract for the home care services they funded. The five agencies agreed on a uniform definition of each service, units of service, reporting requirements, and standards of care for the services, and in 1984, they issued a joint request for proposals to identify qualified home care providers. A committee with representatives from each agency and various citizen advisory groups reviewed the proposals from home care agencies and selected one agency to provide services that would be paid for by the five funding agencies. Subsequently, a home care assessment team was set up to monitor the quality of the services, and procedures were developed to ascertain clients' satisfaction with services and the satisfaction of referral sources

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[17] The client satisfaction questionnaire developed for this purpose is shown in figure 5-4 in ch. 5.

such as physicians and hospital discharge planners.[17]

Based on the success of the previous effort, Tulsa's Long-Term Care Management Authority was established in 1987 to create a single administrative structure that would pool funds and coordinate the delivery of services (557). The organizers of the authority hope that it eventually will coordinate the delivery of all services—acute and long-term care services; in-home, institutional, and community-based services; and publicly and privately funded services. The Long-Term Care Management Authority's first project is a pilot case management program. The pilot program is funded by the Federal Administration on Aging and is intended to provide extended case management for elderly Medicaid and VA clients and to coordinate services provided by various agencies for the same client. A computerized information management system has been developed for the pilot program.

Linn County's Case Management Demonstration Project (Iowa)

The Linn County Case Management Demonstration Project was established in 1981 by a consortium of public and private agencies that provide services for elderly people in Linn county, a rural county in Iowa (80). The agencies in the consortium include the local AAA, which initiated the project; plus the local mental health, family service, United Way, substance abuse, and community action agencies; two hospitals; three home health agencies; an adult day center; a senior center; and two county government agencies. These agencies use a uniform assessment instrument to evaluate elderly people who come to them for services. A case management team composed of representatives of the agencies meets regularly to review new cases, develop care plans, and assign responsibility for managing each new client's care to one of the agencies in the consortium.

In the first years of the Linn County Case Management Demonstration Project, the participating agencies took turns arranging and conducting meetings of the case management team (80,463). In 1986, a coordinator was hired for the project by the Linn County Department of Human Resource Development. Now the member agencies send completed assessment forms to the coordinator who arranges the team's bimonthly meetings. Having a project coordinator has increased the number of cases that can be reviewed and allows for more efficient client tracking. The project has developed a client appeal process and standards for case management, confidentiality, and quality assurance. In the view of its member agencies, the project has reduced fragmentation and duplication of services and minimized turf issues among the agencies.

The North Country Alzheimer's Partnership Project (New Hampshire)

The North Country Alzheimer's Partnership Project, which links people with dementia and their families to services in three rural counties in northern New Hampshire, was created in 1987 by a consortium of public and private agencies (551,614). The project is funded by a 3-year grant from the National Institute of Mental Health. The New Hampshire Divisions of Mental Health and Developmental Services and Elderly and Adult Services coordinate the administration and evaluation of the project.

Individualized care plans are developed for clients of the project on the basis of a comprehensive in-home assessment conducted by nurses from local home health agencies and a social worker from the local Tri-County Community Action Agency. Ongoing case management is provided by Crotched Mountain Community Care, Inc., a private, nonprofit case management agency. Information and referral, public education, family support groups, counseling, and support services are provided by staff of the Tri-County Community Action Agency. The project contracts with six home health agencies to provide in-home services (551,614).

The ACCESS Project in Northwestern Ohio

The ACCESS Project in northwestern Ohio is a project operated by a consortium of 10 public and private agencies that have been receiving funds from the State of Ohio since 1987 to provide people with dementia and their caregivers in a four-county area case management, caregiver education, and in-home and adult day services (156,196). Family Service of Northwest Ohio, a private, nonprofit agency, is the lead agency for the project. State funding for the project was $55,000 for 7 months in fiscal year 1987, $110,000 for fiscal year 1988, and $88.000 a year for fiscal years 1989 and 1990. For in-home and adult day services, the ACCESS Project charges fees to patients and caregivers based on a sliding scale.

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[17] The client satisfaction questionnaire developed for this purpose is shown in figure 5-4 in ch. 5.

Everyone who receives services through the ACCESS project receives case management (196). The ACCESS Project initially charged patients and their caregivers fees based on a sliding scale for the initial patient assessment and ongoing case management, but eventually it stopped charging for these functions. The project summary gave the following rationale:

> Due to the fact that the concept of assessment and case management is ill-defined among the general public, we had a great deal of difficulty explaining to people why they had to pay for that service. As a result . . . we consolidated assessment and the first several hours of case management time and packaged it into what we called a "personal consultant" model. We believed that the use of the "personal consultant" model would be more appealing to the types of caregivers we were getting. We also decided that the ACCESS Project would assume the cost of the service up to the first 6 hours of direct service provided to each client. Through trying this, we discovered that it was a bookkeeping headache to try to keep track of when the first 6 hours of direct service had run out, and once the first 6 hours had expired, we faced the same reluctance among the clients to pay for a service they still did not understand. At this time, we have totally stopped charging for that type of service and have assumed its cost in the project (196).

Despite caregivers' reluctance to pay for case management, a 1989 survey of 69 caregivers who had received ACCESS services found that the great majority of them valued the information and emotional support provided by the project's case managers (619).

ACCESS has a strong caregiver education program. One component of the program is educational workshops conducted in various locations by the East Center for Community Health. The other component is in-home caregiver education, conducted primarily by a nurse from the Medical College of Ohio who uses a video cassette recorder and tapes about Alzheimer's disease to provide individualized caregiver education about dementia and services for people with dementia (156).

Summary and Implications for a National System To Link People With Dementia to Services

The most important observation to be made about the State and community consolidated service systems just described is that such systems are extremely diverse. The systems do have common elements—including, in the State systems, a method of coordinating the administration of various programs at the State level and, in all the systems, methods for coordinating local agencies' functions—but there is great diversity even in these common elements. Oregon coordinates the administration of programs at the State level through a single State agency; Wisconsin uses a human service umbrella agency; and Illinois uses an interagency coordinating committee. Likewise, in each State, different types of agencies have been designated to administer services at the local level—AAAs in Oregon, county social service departments and "county 51 boards" in Wisconsin, and many different kinds of public and private agencies in Illinois. In each of the community service systems, the consortium of public and private agencies that created the system has devised different methods for assigning responsibility for an individual's care to a certain agency or assigning particular functions (e.g., client assessment, ongoing case management, provision of services) to specific agencies.

The second most important observation to be made about the State and community consolidated service systems is that considerable time and effort were required to develop the systems, and difficult organizational and turf issues had to be resolved in the process. Most of the systems were developed incrementally. Among the obstacles they faced were: 1) inflexible requirements and regulations of the Federal programs that pay for services, and 2) administrative and organizational characteristics of State agencies that were established in the past to implement Federal program requirements and, once established, are hard to change (436).

The State consolidated service systems described in the preceding sections differ from the community systems in several ways, although some of the differences are more in degree than in kind. First, the State systems coordinate services for elderly and disabled people in general, or, in the case of Wisconsin, all people who need long-term care; in contrast, some of the community service systems are dementia-specific. Second, the State systems generally coordinate only the functions of public agencies or private agencies under contract to public agencies; in contrast, the community systems coordinate the functions of both public and private agencies. Lastly, the State systems rely more on formal organizational structures and mandated procedures for coordination; in contrast, the community systems seem to rely more on the development of informal working relationships among individual service providers and agencies.

In some ways, it may be easier to create a consolidated service system in a community than in a State because of the smaller number of agencies and individuals that must be involved in a community service system and because of the greater potential for dealing with organizational and turf issues through informal working relationships among individuals. On the other hand, communities lack the authority to allocate and target State funds for services and to designate a single agency at the local level to administer all Federal and State programs that pay for services. These functions require the involvement of the State.

If Congress designated a single category of agencies to constitute a national linking system, States and communities that have developed consolidated service systems which are administered by agencies other than the designated agencies would have to change their systems or, alternatively, accept the existence of several systems—an outcome they have already spent considerable time and effort to avoid. Conversely, if Congress allowed each State to select the agencies that would constitute the linking system in that State, States that have developed consolidated service systems could incorporate the components of the linking system into their existing service systems. Presumably, some States would designate consortiums of agencies to constitute the linking system in some communities, particularly communities where a consortium of agencies has already established a service system that links people to services.

Consolidated service systems reduce the complexity and fragmentation of the service environment for the people they serve and generally make it easier for those people to connect to appropriate services, but many of the existing systems do not serve all types of people with dementia. Some systems do not serve people under age 60 or 65, and many State systems focus primarily or exclusively on low-income people and/or people who are severely functionally impaired. Targeting public funds for services to low-income people and people who are severely functionally impaired seems entirely appropriate, but such targeting is not necessarily appropriate for linking functions. People with dementia and their families need help in linking to services at all stages of the patient's illness, including the early stages when the patient is not severely impaired. Likewise, patients and families with all levels of income and assets and patients under age 60 or 65 need help in linking to appropriate services.

Another reason why some consolidated service systems may not be completely effective in linking people with dementia to services is because they emphasize case management more than the three other components that OTA has concluded are essential for an effective linking system (i.e., public education, information and referral, and outreach). Although the local agencies that administer long-term care services in Oregon, Wisconsin, and Illinois also provide or contract for information and referrals (436,587), the primary emphasis in some systems that administer long-term care services is on providing case management for people who are eligible for the services.

Service systems that emphasize case management more than other linking functions and provide case management primarily for low-income and severely impaired people do so partly because of resource limitations and partly because of the systems' objectives and mission (i.e., they are responsible for allocating publicly funded services to people who are eligible for the services). Any of the systems could be modified to provide all four linking functions, thus expanding their mission and objectives to include linking all kinds of people to services. To do so would require more resources.

Lessons From Long-Term Demonstration Projects for the Development and Operation of Long-Term Care Service Systems

Beginning in the 1970s, Federal, State, and local governments and private foundations sponsored many long-term care demonstration projects. The primary purpose of the projects was to demonstrate that making available expanded in-home and community services could reduce the use of nursing home care and ultimately reduce total expenditures for long-term care. Case management was a central component of virtually all the demonstration projects.

Recently, Kemper and colleagues analyzed the findings of 16 long-term care demonstration projects (406,407).[18] They found that the use of nursing homes was slightly lower among demonstration participants (i.e., the people who received case management and had access to expanded in-home and community services) than for members of control groups. On the other hand, the cost of case management and expanded in-home and community services for demonstration participants generally exceeded any savings realized because of participants lower use of nursing homes.

Other commentators who have analyzed long-term care demonstration projects, including the projects analyzed by Kemper and colleagues, have reached essentially the same conclusions (see, e.g., Capitman (112), Hedrick and Inui (312), Piktialis and MacAdam (662); and Weissert (896)). These commentators have pointed out that in order to produce cost savings, case management and expanded in-home and community services would have to be targeted more precisely to people who without the services would be very likely to be admitted to a nursing home and that such precise targeting is probably not possible at present.

In summarizing their findings and pointing toward future directions for research and policy debate, Kemper and colleagues said:

> Based on a review of community care demonstrations, we conclude that expanding public financing of community services beyond what already exists is likely to increase costs. Small nursing home cost reductions are more than offset by increased costs of providing services to those who would remain at home even without the expanded services. However, expanded community services appear to make people better off and not to cause substantial reductions in family caregiving. *Policymakers should move beyond asking whether expanded community care will reduce costs to addressing how much community care society is willing to pay for, who should receive it, and how it can be delivered efficiently* [emphasis added] (406).

Even though the long-term care demonstration projects generally did not show that the government could save money by substituting in-home and other community services for nursing home care, many of the demonstration projects evolved into ongoing programs.[19] Furthermore, the long-term care demonstration projects produced valuable knowledge and experience in implementing long-term care service systems. That knowledge and experience, coupled with knowledge and experience derived from ongoing State and community service systems, can be helpful to other States and communities that are developing long-term care service systems.

A particularly valuable source of information about long-term care service systems is the National Long-Term Care Channeling Demonstration (502). The Channeling demonstration, which was funded by the U.S. Department of Health and Human Services from 1980 to 1985, tested two case management models:

- a "basic" model, in which case managers helped clients locate and arrange services but had very limited funds to purchase services for them; and
- a "financial control" model, in which case managers not only helped clients locate and arrange services but had substantial funds to purchase services for them.

Case managers in the financial control model were much more involved than case managers in the basic model in allocating services and funding for services. Therefore, some findings of the demonstration about differences between the two models are relevant to one of the major policy questions raised in chapter 1—whether the agencies that are selected to constitute a national linking system should also allocate services and funding for services. Case managers in the basic model, who were less involved in allocating services and funding for services, were able to spend comparatively more time on directly helping clients, whereas case managers in the financial control model spent more time on administrative tasks and paperwork associated with ordering services (502). Ongoing case management cost more in the basic model ($51 per client per month) than in the financial control model ($35 per client per month). Obviously, however, the average cost to the demonstration of services arranged for clients was much lower in the basic model ($38 per client per month) than in the financial control model ($471 per client per month) (501). Both models reduced unmet service needs and increased informal caregivers' confidence that they would receive needed services and their satisfaction with service arrangements, but these outcomes were greater in the financial control model than in the basic model (502).

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[18] The 16 projects Kemper and colleagues reviewed were: 1) the Worcester Home Care Project; 2) National Center for Health Services Research Day Care/Homemaker Experiment; 3) Triage; 4) Washington Community-Based Care; 5) the ACCESS Project; 6) Georgia Alternative Health Services; 7) Wisconsin Community Care Organization; 8) On Lok Community Care Organization for Dependent Adults; 9) Organizations Providing for Elderly Needs; 10) the Multipurpose Senior Services Project (MSSP); 11) South Carolina Community Long-Term Care; 12) the Nursing Home Without Walls Program; 13) New York City Home Care; 14) Florida Pentastar; 15) San Diego Long-Term Care; and 16) the Channeling Project (406,407).

[19] Triage, for example, evolved into Connecticut Community Care, Inc., a private nonprofit case management agency discussed in ch. 1. On Lok Senior Health Services, as discussed in ch. 8, continues as a consolidated service delivery system in San Francisco and is currently being replicated in several locations nationwide. The Multipurpose Senior Services Project (MSSP) in California and the Nursing Home Without Walls in New York are ongoing programs that were discussed earlier in this chapter.

The Channeling demonstration project also had findings that bear on another policy question raised in chapter 1—whether the agencies that are selected to constitute a national linking system should or should not be service-providing agencies (i.e., agencies that provide services that go beyond linking functions). The Channeling demonstration project was implemented in 10 sites across the country. Six of the host agencies were AAAs (503). The other four host agencies were service-providing agencies. According to Channeling staff, case managers in the four service-providing agencies were generally able to maintain their independence and not did overuse their own agencies' services in preference to other agencies' services (30). This finding counters one of the primary arguments against designating service-providing agencies to constitute a national linking system.

The Channeling demonstration project also generated information that pertains to the implementation of case management in a service system, including the impact of differences in the size of case managers' caseloads and the relative strengths and weaknesses of nurses and social workers as case managers in such systems (34,503). Other useful findings of the demonstration pertain to procedures for selecting and contracting with community service providers and monitoring the costs and quality of services (503).[20] All of these findings are relevant to the design of a system to link people with dementia to services.

CONCLUSION

As described in this chapter, many States have programs that link at least some people with dementia to services, and some States and communities have service systems that link some people with dementia to services. The chapter has pointed out both the existence and the diversity of those programs and systems—factors that have sometimes been given insufficient consideration in the development of Federal programs and policies for health care, long-term care, social, and other services for elderly and disabled people.

As noted throughout the chapter, the diversity of State linking programs and State and community services systems makes it difficult to design a national linking system that will fit with the existing programs and systems. The next chapter describes 11 categories of agencies Congress might designate to constitute the linking system nationwide and discusses several reasons for designating a single category of agencies to constitute such a system. On the other hand, by designating a single category of agencies to constitute the system, Congress would risk duplicating or disrupting existing State linking programs and State and community service systems. For this reason, Congress might choose instead to allow each State to designate the agencies that will constitute the linking system in that State.

There are important differences between linking programs and consolidated service systems. Linking programs are easier to establish than consolidated service systems because the programs can be established at the State or community level without substantially changing the structure, functions, or relationships among existing agencies and without engendering the intense organizational and turf issues that must be overcome in the process of creating a consolidated service system. On the other hand, linking programs do nothing to reduce the fundamental complexity and fragmentation of the service environment, so the problems that patients and families encounter in connecting to appropriate services because of the complexity and fragmentation of the service environment remain.

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[20] For more information about Channeling, the interested reader is referred to a publication of the U.S. Department of Health and Human Services, *The Evaluation of the National Long-Term Care Demonstration: Final Report: Executive Summary* (502). That publication summarizes the project results and lists 25 additional evaluation reports on specific aspects of the project and 12 training guides and technical assistance documents developed for it.

A few States and communities have gone a considerable way in creating consolidated service systems. Their purposes in developing these systems have been to reduce the complexity and fragmentation of services at the community level; to connect people to services they need; to gain control over public, and especially State, expenditures for health care and long-term care services; and ultimately to shift some of the public funds now spent on nursing home care to in-home and community services. These systems would be particularly likely to be disrupted if Congress mandated a single category of agencies to constitute the national linking system.

Finally, the chapter has described linking programs and service systems that are intended to serve elderly people or people of all ages and linking programs and systems that are intended to serve only people with dementia. These programs provide alternate models for a national linking system. The pros and cons of mandating a linking system that is dementia-specific v. a system that is dementia-capable and dementia-friendly but not dementia-specific are discussed in chapter 1.

Chapter 8

Agencies That Might Constitute a Uniform National Linking System

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Chapter 8

Agencies That Might Constitute a Uniform National Linking System

INTRODUCTION

As described in chapter 7, all States have linking programs, and some States and local communities have service systems that help families and others locate and arrange services and sources of funding for services for people with dementia. These State and community programs and systems are extremely diverse and are administered by a great variety of agencies. Some of the programs and systems are dementia-specific, and others are not. If Congress established a national system to link people with dementia to services, it could allow States to decide which agencies should constitute the linking system in their jurisdiction. Under this option, each State could be given the choice of either: 1) selecting a single category of agencies to constitute the linking system statewide, or 2) selecting agencies of different types or a consortium of agencies to constitute the linking system in different local communities.

An alternate approach that Congress might consider would be to establish a national linking system in which the Federal Government would select a single category of agencies to constitute the system nationwide. Whether Congress should establish a national linking system composed of a single category of agencies designated by the Federal Government or one composed of agencies designated by individual States is an important policy issue discussed in chapter 1. A system composed of a single category of agencies nationwide might be more recognizable to the public than a system composed of different types of agencies in different States and might be better suited to helping long-distance caregivers of people with dementia find services. One of the major drawbacks to this approach is that the designation of a single category of agencies to constitute the linking system nationwide would disrupt some existing State programs and service systems, particularly programs and systems that utilize agencies that are not selected or that are unique to a particular State or locality.

This chapter analyzes 11 categories of agencies that Congress could, at least in theory, designate as the basis of a national linking system for people with dementia if Congress chose to establish a system composed of a single category of agencies nationwide:

1. area agencies on aging,
2. community mental health centers,
3. community health centers,
4. Alzheimer's Association chapters,
5. Family Survival Project,
6. States' regional Alzheimer's diagnostic and assessment centers,
7. hospital-based geriatric assessment programs,
8. home health agencies,
9. social health maintenance organizations,
10. On Lok Senior Health Services, and
11. adult day centers.

The Office of Technology Assessment (OTA) compiled this list by identifying categories of agencies that met the following criteria:

- agencies in the category are currently engaged in linking at least some people with dementia to services;
- agencies in the category are discrete entities that could be identified and funded directly from the Federal level; and
- agencies in the category are currently part of a nationwide "system" of agencies (e.g., area agencies on aging, Alzheimer's Association chapters) or could conceivably be expanded to serve the entire country (e.g., On Lok, Family Survival Project).

OTA believes that the 11 categories of agencies analyzed in this chapter include all the categories of agencies that meet these criteria. Inclusion of a category of agencies in this analysis does not mean that OTA considers the category of agencies currently capable of constituting a national linking system for people with dementia, but only that the category of agencies meets the criteria for inclusion in the analysis.

State and local government agencies, such as State or local departments of health and social services, are not included in the analysis in this chapter; the reason is that States and local governments determine the functions of their own agencies, and specific State and local government agencies could not be designated by the Federal Government to perform the linking functions. If Congress allowed States to designate the agencies that would constitute the linking system, States could designate any State or local government agency they chose. Some of the State and local government agencies that are currently involved in linking people with dementia to services are described in chapter 7.

Each subsequent section of this chapter provides a brief overview of a single category of agencies and presents the available information about who is served by that category of agencies and the extent to which the agencies serve people with dementia. Each section then analyzes its particular category of agencies in terms of its current performance of the four functions OTA deems critical to an effective system to link people with dementia to services:

1. public education,
2. information and referral,
3. outreach, and
4. case management.

As defined in this report, *public education* means providing general information to help people understand dementia and the kinds of services that may be helpful for individuals with dementia. *Information and referral* means providing information about and referrals to specific services and sources of funding for services in the community. *Outreach* means using an active method to identify people with dementia and caregivers who need assistance but are unlikely to respond to public education programs or to contact an information and referral source on their own. *Case management* means assessing a client's needs, developing a plan of care for the client, arranging and coordinating services for the client, monitoring and evaluating services the client receives, and reassessing the client's situation as the need arises.

An important policy question raised in chapter 1 of this report is whether the agencies that constitute a national system to link people with dementia to services should be agencies that allocate services and funding for services. In the analysis that follows, the extent to which each category of agencies allocates services and funding for services is indicated.

OTA does not select any single category of agencies as the category that should be designated to constitute a national linking system. In fact, OTA's main conclusion from the analysis in this chapter is that no single category of agencies is currently capable of functioning effectively as a national linking system for people with dementia and their caregivers. As discussed in the following sections, each of the 11 categories of agencies has positive features that would contribute to its ability to serve as the basis of a national linking system, but each category also has one or more features that would have to be modified for agencies in the category to function effectively as such a system.

The identification of features of each of the 11 categories of agencies that would have to be modified for agencies in the category to function effectively as a national system to link people with dementia to services is not intended to be critical of the agencies. Linking people with dementia to services is not the primary objective or even one of the primary objectives of some of the 11 categories of agencies, and each category of agencies has other important objectives. Moreover, all of the agencies operate within resource constraints. In the case of some of the categories of agencies, it would take a significant redirection of the agencies' mission and resources to function effectively as a national system to link people with dementia to services. Such a redirection of those agencies' mission and resources would compromise their ability to fulfill other objectives, including the provision of services for other client populations.

The congressional committees that requested this study asked OTA to identify particular agencies that are doing a good job of linking people with dementia and their caregivers to services, and OTA found at least one "model" agency in each of the 11 categories of agencies. In the case of Family Survival Project, On Lok Senior Health Services, and social health maintenance organizations, the original agencies are themselves models. The "model" agencies in the other categories are highlighted in the shaded boxes in this chapter. The agencies in each of these categories differ from one another in many ways that affect their capacity to link people with dementia to services, however; and it is important to emphasize that the "model" agencies are often the exception rather than the rule.

It is by no means clear that Congress should designate a single category of agencies to constitute a national linking system for people with dementia. If Congress decided instead to allow States to designate the agencies that would constitute the linking system in their jurisdiction, the analysis in this chapter might be useful to individual States in selecting those agencies and in determining how the agencies they selected might have to be modified to function effectively in linking people with dementia and their caregivers to services.

AREA AGENCIES ON AGING

Area agencies on aging (AAAs) are public or private nonprofit agencies that are designated to receive Federal Older Americans Act funds to plan, coordinate, and arrange services for elderly people. AAAs are part of a nationwide network of agencies developed since the enactment of the Older Americans Act (Public Law 89-73) in 1965. This network, often referred to as the "aging network," includes:

- the Administration on Aging within the U.S. Department of Health and Human Services,
- 57 State units on aging,
- 670 AAAs, and
- thousands of local agencies and individuals that provide services for elderly people through contracts or other agreements with AAAs (69,575).

OTA has included AAAs in its analysis of agencies that might constitute a national system to link people with dementia to services for several reasons. One reason is that some AAAs provide public education, information and referral, outreach, and case management for elderly people, including some people with dementia. In addition, AAAs are mandated by the Older Americans Act to provide for the establishment of information and referral services for elderly people and to ensure that an "adequate proportion" of the Older Americans Act funds allocated to the AAA are spent for "services associated with access to services," including information and referral and outreach for elderly people (818). The great majority of people with Alzheimer's disease and other diseases that cause dementia are elderly,[1] and these provisions of the Older Americans Act would seem to include them.

Another reason that OTA has included AAAs in its analysis of agencies that might constitute a national system to link people with dementia to services is that AAAs already exist in many parts of the country. Also since AAAs are part of a nationwide network, they may be able to help long-distance caregivers locate and arrange services for a person with dementia who lives in a different area of the country.

One observer has suggested using AAAs and other aging network agencies to create a nationwide network of highly visible and easily accessible "Aging Resource Centers for Help" to which elderly people and their families could turn for assistance:

> Perhaps the most pressing need in our aging society is for a highly visible distinctive site in every community—that is part of a nationwide, inter-community network of such sites—to which older people and their families can turn for beginning the process of getting help, reliably. The Title III network is ideally situated to fulfill this need, if it can become more visible, in a uniform fashion, in communities nationwide. It has already evolved into an infrastructure of agencies throughout the country (68).

If there were such a nationwide network of resource centers for elderly people, it probably could be adapted to meet the needs of people with dementia and their caregivers as well.

Overview of the Agencies

As originally enacted in 1965, Title III of the Older Americans Act established a program of Federal grants to States for the development of "a comprehensive and coordinated system" of services to help elderly people live independently in their communities and in their homes (818). The Older Americans Act established the Administration on Aging as the Federal agency responsible for carrying out all of its provisions, including the administration of the Title III program of Federal grants to States.

The Older Americans Act of 1965 required each State to designate a single State agency—commonly referred to as a "State unit on aging"—to formulate a plan for developing the system of community services envisioned in the act and to oversee the use of Title III funds in the State (818). Currently, there is a State unit on aging in each of the 50 States and in the District of Columbia, Puerto Rico, the Virgin Islands, Guam, American Samoa, the Northern Mariana Islands, and the Trust Territory of the

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[1] An analysis of available data on the prevalence of dementia that was conducted for OTA in 1985 found that individuals under age 65 accounted for less than 1 percent of all people with severe dementia and less than 10 percent of all people with mild or moderate dementia (152).

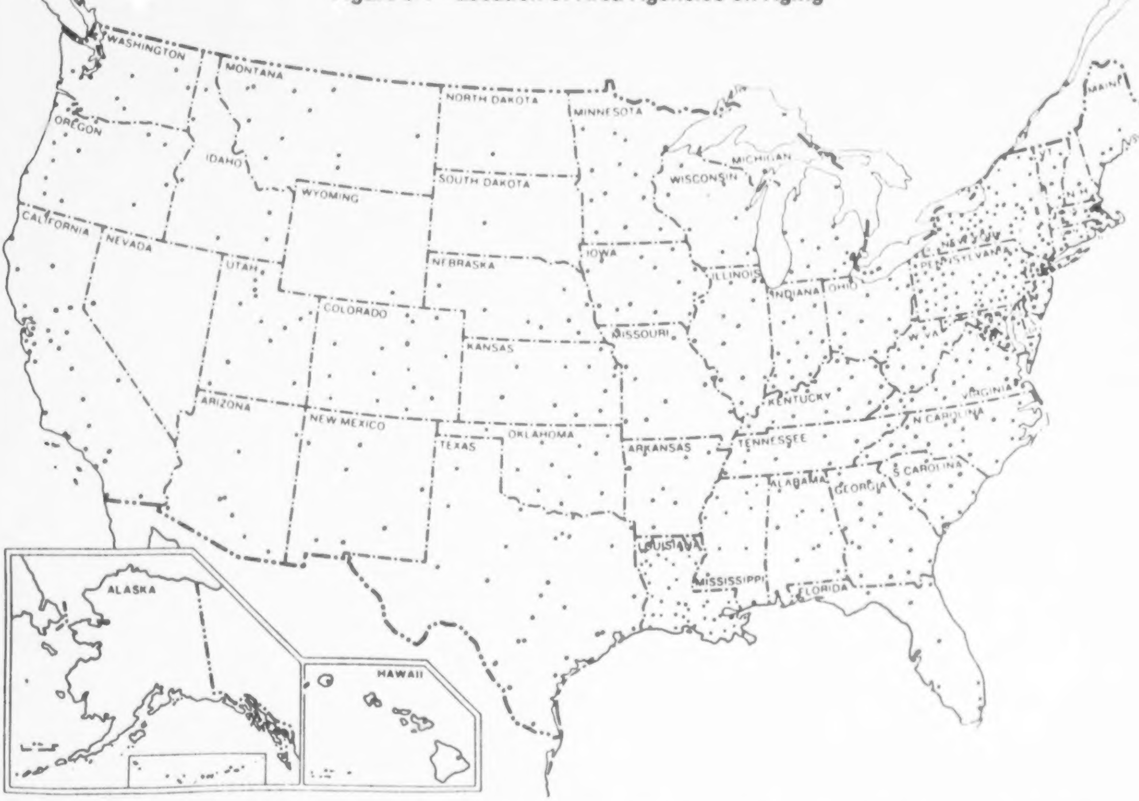
Pacific Islands (566). The names of State units on aging vary from State-to-State (e.g., the Michigan Office of Services to the Aging, the Nebraska Department on Aging, the Mississippi Council on Aging, the New Mexico State Agency on Aging, the New Jersey Division on Aging) (566). State units on aging operate not only as the agencies required by the Older Americans Act, but also as components of State and territorial government, and as a result, their functions vary greatly in different States and territories.

The Older Americans Act has been amended 11 times since 1965. In 1973, the act was amended to require each State or territory seeking Title III grants to divide its jurisdiction into "planning and service areas" and to designate an AAA to plan, coordinate, and arrange services for elderly people in each area. Sparsely populated States or territories are allowed to treat their jurisdictions as one planning and service area and to designate only a single AAA, and 13 States and territories have chosen to do so; in those areas, the State unit on aging serves as the AAA (374,575). All but a few States have designated more than one AAA. New York, with 58 AAAs, has the most (575). Figure 8-1 shows the distribution of AAAs throughout the country.

States with a similar number of residents over age 60 do not necessarily have the same number of AAAs. For example, Georgia, Virginia, and Wisconsin, each of which has about 850,000 residents over age 60, have 18, 26, and 6 AAAs respectively (566). Likewise, South Dakota and Minnesota, each of which has about 130,000 residents over age 60, have 1 and 11 AAAs respectively. In terms of the number of elderly people in their planning and service area, AAAs are not uniform nationally.

About two-thirds of AAAs are public agencies, including county or city government agencies and council of government, regional planning, and economic development agencies. The remaining

Figure 8-1—Location of Area Agencies on Aging


WASHINGTON
MONTANA
NORTH DAKOTA
MINNESOTA
MAINE
OREGON
IDAHO
WYOMING
SOUTH DAKOTA
WISCONSIN
MICHIGAN
VT.
N.H.
NEW YORK
PENNSYLVANIA
CALIFORNIA
NEVADA
UTAH
NEBRASKA
IOWA
ILLINOIS
INDIANA
OHIO
COLORADO
KANSAS
MISSOURI
W. VA.
VIRGINIA
KENTUCKY
N. CAROLINA
ARIZONA
NEW MEXICO
OKLAHOMA
TEXAS
ARKANSAS
TENNESSEE
S. CAROLINA
ALABAMA
GEORGIA
LOUISIANA
MISSISSIPPI
FLORIDA
ALASKA
HAWAII

SOURCE: National Association of Area Agencies on Aging, *A Directory of State and Area Agencies on Aging, 1987-1988* (Washington, DC: 1988).

one-third of the AAAs are private, nonprofit agencies (575). The term "area agency on aging" is a generic one; the names of specific AAAs vary (e.g., Active Aging, Inc., Community Council of Greater Dallas, District 5 AAA, Western Reserve AAA) (566). Like State units on aging, many AAAs operate not only as agencies required by the Older Americans Act, but also as components of county or city government or private agencies that have many functions other than those mandated by the act. This fact explains some of the differences among AAAs that are discussed in this section.

Each AAA is required by the Older Americans Act to prepare annually and submit to the State unit on aging a plan for the development of a comprehensive and coordinated system of services for elderly people in the AAA's planning and service area (818). The plan developed by an AAA must ensure that elderly people in the AAA's area have access to the following services:

- nutrition services, including congregate and home-delivered meals;
- access services, including transportation, outreach, and information and referral;
- in-home services, including homemaker and home health aides, visiting and telephone reassurance, chore maintenance, in-home respite care, minor modification of homes to accommodate frail, older individuals, and supportive services for families caring for older people; and
- community services, including adult day care, senior centers, legal assistance, and adult protective services (374,566,818).

To implement its area plan, each AAA is required by the Older Americans Act to arrange for the provision of services with local providers and to coordinate the services it provides or pays for with the services of other community agencies and voluntary organizations (818). AAAs often contract with other agencies and individuals to provide Title III-funded services. The Older Americans Act specifically forbids AAAs to provide, rather than to contract for, a Title III-funded service unless the service:

1. is directly related to an AAA's administrative functions,
2. can be provided at less cost by the AAA than any other provider, or
3. in the judgment of the State unit on aging, must be provided by an AAA to ensure an adequate supply (818).

It has been estimated that in 1986, AAAs throughout the country contracted with more than 26,000 service providers (212).

It is important to note that, in general, AAAs are not required by the Older Americans Act to *provide* services, but rather to plan and arrange for their provision. Many AAAs do provide a variety of services, sometimes for the three reasons just cited and sometimes because, as mentioned earlier, AAAs are public and private agencies that have many functions other than those mandated by the Older Americans Act. On the other hand, some AAAs operate almost exclusively as planning agencies and provide few, if any, services. Relevant to this point, a 1987 study of 25 AAAs by the Office of the Inspector General of the U.S. Department of Health and Human Services found that all the AAAs considered the development of a comprehensive and coordinated system of community services for elderly people—not the provision of services—to be their highest priority (853).

For fiscal year 1989, Congress appropriated $858 million for Title III programs.[2] About two-thirds of this was for nutrition services (mainly congregate meals), and the remaining one-third was for all other services authorized under Title III (829). Title III funds are allocated to State units on aging according to a formula that is based in part on each State's portion of the national population over age 60 (818). Although State units on aging derive a significant portion of their budgets from Title III funds, they also receive funds from other sources, including the Federal Social Services Block Grant program, the Medicaid 2176 Home and Community-Based Waiver program, and State general revenues (374,575).

State units on aging allocate most of the Title III funds they receive to AAAs (374,575). To allocate the funds, State units are required by the Older Americans Act to develop and apply a formula that takes into account the geographic distribution in the State of elderly people with the greatest economic and social need (818). The amount of Title III funds received by individual AAAs varies, depending primarily on the overall Title III funds available to a State and the formula used by the State for allocating the funds (69,575). In addition to Title III funds, many AAAs receive funds from other sources, including Federal, State, and local government agencies and programs, foundation grants, and voluntary contributions from elderly service users (65,170,605).

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[2] The amount of Federal funding for programs under Title III of the Older Americans Act has always been small in comparison to the amount for other Federal programs that serve elderly people (828). For fiscal year 1987, for example, the $700 million appropriated for Title III programs represented less than 0.25 percent of the $270 billion annual Federal outlays for benefits for elderly people (68).

Who Is Served

People over age 60 are eligible for services paid for with Title III Older Americans Act funds. Some AAAs use non-Title III funds (e.g., funds from other Federal, State, and local government programs, private contributions, and other sources) to serve younger people (170,605,756). If an AAA uses only Title III funds to pay for a specific service, however, people who are under age 60 generally are not eligible for the service.

AAAs are prohibited from using means testing to determine elderly people's eligibility for services paid for with Title III funds, and they may not charge fees for these services, although they may request voluntary contributions.[3] Because Title III-funded services are not means tested, AAAs are sometimes able to provide or pay for services for elderly people who do not meet the financial eligibility criteria for other programs (575,828).

The Older Americans Act requires that AAAs give priority to ensuring that the service needs of elderly people with the greatest economic or social need are met. Economic need is defined as having an income level at or below the federally established poverty levels. In 1985, 43 percent of all elderly people who received Title III-funded services had incomes below these levels (266). Social need is defined in terms of noneconomic factors, including physical and mental disabilities, language barriers, and cultural, social, or geographic isolation. OTA is not aware of any information about the percent of elderly people who received Title III-funded services who have physical or mental disabilities or were socially or geographically isolated. In 1987, minority elderly people constituted 16 percent of all people who received Title III-funded services (454).

The extent to which AAAs serve people with dementia is unclear. The results of several studies indicate that some, and perhaps many, people with dementia receive services of various kinds through AAAs (193,605,756,934), but no data are available on the total number of people with dementia who receive services through AAAs. Moreover, as noted later in this section, some people with dementia who receive services through AAAs may not be identified as having dementia.

In 1986, the New York City Department for the Aging surveyed all State units on aging and all AAAs to determine what services they provided—either directly or through arrangements with other providers—for people with Alzheimer's disease and their families (605). Forty-six State units on aging and more than 200 AAAs responded to the survey. Some of the AAAs that responded said that they were providing the same services for people with Alzheimer's disease as for other elderly people, but many of the AAAs reported that they were providing or paying for some special services for people with Alzheimer's disease and their families. The special services mentioned most frequently were caregiver support groups, educational programs and materials, respite care, and adult day care. Many of the AAAs reported that they had sponsored training programs about Alzheimer's disease and dementia for professionals and other service providers. Many of the AAAs also said that they had formed cooperative alliances with Alzheimer's Association chapters and other agencies in an effort to meet the needs of Alzheimer's patients and their families.

A 1987 mail survey of AAAs in Virginia had similar findings (193). Information was obtained about services that were provided or paid for by 25 Virginia AAAs for people with Alzheimer's disease and their caregivers. Caregiver support groups—provided or sponsored by 22 of the AAAs—were by far the most frequently mentioned service. Other services that were mentioned by about one-third of the AAAs were information and referral, congregate meals, adult day care, respite care, and other in-home services. A few of the AAAs said they had provided or paid for an Alzheimer's disease newsletter, brochure, or videotape, and a few had included information about Alzheimer's disease in their AAA newsletter. Most of the AAAs reported that they had sponsored or co-sponsored workshops, educational programs, or community meetings on Alzheimer's disease for caregivers, service providers, and/or the general public, and most of the AAAs (20 of the 25 AAAs that responded to the survey) considered these educational programs to be their most successful dementia-specific services.

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[3] As discussed later in this section, some AAAs do use means testing to determine people's eligibility for services paid for with non-Title III funds, and some AAAs charge fees for such services (353,462).

In contrast to the findings of these surveys, OTA has heard from many people, including Alzheimer's caregivers, Alzheimer's advocates, health care and social service professionals, and others, that AAAs are not providing adequate services for people with dementia. In part, these complaints may reflect some people's lack of awareness of the services provided by AAAs, especially their lack of awareness that some of the services provided by other agencies or organizations are, in fact, funded in whole or in part by an AAA. The complaints probably also reflect some people's expectation that AAAs *should* provide services for people with dementia—an expectation they may not have for some of the other categories of agencies discussed in this chapter. Nevertheless, the complaints are clear and pervasive. Given these complaints, OTA has been surprised by the number of AAAs that report that they offer special services for people with dementia.

In addition to hearing complaints about the lack of sufficient AAA services for people with dementia, OTA has been told that some AAA staff members are uninformed about Alzheimer's disease, dementia, and potentially beneficial services for people with dementia and/or unresponsive to the needs of people with dementia and their caregivers (see, e.g., the case study of Mrs. D in ch. 1). No data are available to determine whether these allegations reflect isolated incidents or a more general problem.

The Administration on Aging has funded many initiatives to provide training for the staff of aging network agencies about Alzheimer's disease and dementia and to encourage aging network agencies to provide or pay for services for people with dementia. These initiatives include:

- the publication in 1983 and 1984 of four handbooks on Alzheimer's disease and how to work with Alzheimer's patients and their families (851);
- training sessions on Alzheimer's disease for State unit on aging and AAA personnel, as required by the 1984 amendments to the Older Americans Act;
- a multiyear initiative to encourage AAAs and other aging network agencies to develop support groups for caregivers of people with dementia;
- many research and demonstration projects on various kinds of services and methods of working with people with dementia and their caregivers (605); and
- the designation in 1989 of a "National Resource Center on Alzheimer's Disease" at the University of Southern Florida.

The Older American's Act contains several specific references to services for people with Alzheimer's disease and their caregivers. The act requires that an AAA's annual plan ensure that an adequate proportion of Title III funds allocated to the AAA will be spent for in-home services, including "supportive services for families of elderly victims of Alzheimer's disease and related disorders" (818). The act also requires that an AAA's annual plan show how Title III-funded services will be coordinated with the activities of community organizations established to help people with Alzheimer's disease and their families (818). In addition, in 1987, Congress created a new section of Title III specifically to authorize in-home services for "frail older individuals" (818) "Frail" is defined in the new section of the law as "having a physical or mental disability, including Alzheimer's disease or a related disorder with neurological or organic brain dysfunction, that restricts an elderly person's ability to perform daily tasks or threatens his/her capacity to live independently" (818). It is too soon to know what effect this new program will have.

Linking Functions

Information and Referral

The Older Americans Act requires that each AAA's area plan "provide for the establishment and maintenance of information and referral services in sufficient numbers to assure that all older individuals within the planning and service area covered by the plan will have reasonably convenient access to such services" (818). Some AAAs contract with other agencies to provide information and referrals for elderly people, and some AAAs provide information and referrals themselves (756). A 1988 survey of State units on aging conducted by the National Association of State Units on Aging found that AAAs in the 41 States that responded to the survey were operating 320 information and referral programs and contracting for an additional 697 information and referral programs (577).[4] In some planning and service areas, the AAA was operating or contracting for more than one information and referral program. The most frequently reported reasons for this practice were geography and language or nationality (577).

It is clear that many AAAs provide or contract for information and referral programs for elderly people, but for the purpose of this OTA study, it is important to emphasize that some AAAs do not provide information and referrals themselves. A member of the advisory panel for this OTA study who contacted many AAAs in the course of setting up IBM's Eldercare Referral Service reported that some of the AAAs she contacted said that they were not appropriate agencies to provide the kind of individualized referrals that are part of the IBM Eldercare program (659).[5] These AAAs pointed out that they are primarily planning agencies and that they do not provide information and referrals for individuals.

No data are available on the number of people with dementia and their caregivers who are currently served by information and referral programs provided or funded by AAAs. In 1985, the Eastern Massachusetts Alzheimer's Association Chapter conducted a mail survey of Massachusetts AAAs and a few other agencies in the State (756). All of the 24 agencies that responded to the survey, including 22 AAAs, indicated that they provided information and referrals for people with dementia, but about one-quarter of the agencies were unable even to estimate the number of people with dementia they had served because they did not keep records of the diagnoses or conditions of the people for whom they provided information and referrals. An exploratory study conducted for OTA in Cuyahoga County, OH, which is described in detail in chapter 2, found that many types of agencies that said they provided information and referrals for people with dementia in the county did not keep records on the people they served by either diagnosis or condition (186). The fact that an agency does not keep records on the people it serves by their diagnosis or condition does not prove that the agency staff member who provides information and referrals is unaware of clients' diagnoses or conditions. It suggests that this could be the case, however. If a person with dementia is not identified as such by an information and referral source, the person may not be referred to appropriate services.

Another concern about the referrals provided by some AAAs for people with dementia is the accuracy and comprehensiveness of the AAAs' lists of services. AAAs in many communities maintain lists of services for elderly people, but anecdotal evidence indicates that these resource lists vary in the extent to which they are accurate and comprehensive with respect to services that may be needed for people with dementia (246).

In order to improve information and referral for people with dementia, some States have established statewide dementia-specific information and referral programs. Chapter 7 discusses 13 such programs, six of which are administered by the State agency that also functions as the State unit on aging. Some AAAs have also established dementia-specific information and referral programs. The New York City Alzheimer's Resource Center, which was established in 1984 by the New York City Department for the Aging—a department of municipal government and the largest AAA in the country, is probably the most ambitious of these programs (see box 8-A). The resource center maintains up-to-date information on all services available to Alzheimer's patients and their families in the area and functions as an information clearinghouse, answering 125,000 inquiries a year (605). It also provides public education and a variety of direct services for people with dementia and their caregivers.

Because AAAs are part of a nationwide network, they have the potential to connect long-distance caregivers to sources of information about services for elderly people who are living in other areas of the

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[4] The 1988 survey also found that 32 States had toll-free statewide information and referral programs; 18 of these statewide programs were specifically for elderly people, and many of them were operated by the State agency that functions as the State unit on aging (577). State information and referral programs for elderly people and for people with dementia are discussed in ch. 7.

[5] IBM's Eldercare Referral Service is discussed in ch. 1.

Box 8-A—The New York City Alzheimer's Resource Center

The New York City Department for the Aging, a department of municipal government and the largest area agency on aging in the country, offers assistance to Alzheimer's disease patients, caregivers, and professionals through the New York City Alzheimer's Resource Center. Established in 1984 with funds from the Brookdale Foundation and the City of New York, the Alzheimer's Resource Center is the first municipally sponsored comprehensive information, referral, and counseling service in the Nation.

Information and Referral—The Alzheimer's Resource Center operates a comprehensive information and referral program and works with a variety of other organizations to link Alzheimer's patients, their families, and others to appropriate programs and services in the city. The Alzheimer's Resource Center maintains current information on all services available to Alzheimer's patients and their families in New York City and functions as an information clearinghouse, responding to over 125,000 inquiries a year. The center has an interdisciplinary staff of professionals who provide guidance to families and caregivers on public benefits and entitlement programs, nursing home placement, home care services, respite, and adult day care. The center is open from 9:00 a.m. to 5:00 p.m. Monday through Friday.

Public Education—Public education efforts to help people understand the nature of Alzheimer's disease and learn about available resources have been a major activity of the Alzheimer's Resource Center. The center reaches the public in a variety of ways, including publications, mass transit advertising, radio and television public service announcements, press releases from the mayor's office, and direct mailings. The center has found that publications are a valuable method of providing help to caregivers and others in understanding Alzheimer's disease and the resources available to them. Several editions of a 100-page resource guide, *Alzheimer's Disease: Where To Go for Help in New York City*, have been prepared by the Alzheimer's Resource Center in cooperation with the New York City Chapter of the Alzheimer's Association. Cooperative activities with other organizations are an important aspect of the center's public education and other activities. Each year, the Alzheimer's Resource Center and the New York City Chapter of the Alzheimer's Association sponsor a citywide mayoral conference, with over 1,000 participants, to educate people about Alzheimer's disease, draw attention to Alzheimer's programs in the New York City area, and promote new Alzheimer's programs. The center also works with private sector companies and unions to conduct health fairs and lunchtime training and support groups for caregivers.

Provision of Services—In addition to providing educational programs and materials and information and referrals, the Alzheimer's Resource Center has undertaken several efforts to provide services not available elsewhere.

- A family counselor provides free one-on-one *professional counseling* to family members who are in crisis.
- The center operates a free *in-home respite* program for families who are ineligible for Medicaid but unable to afford the purchase of private home care. The program provides for a maximum of 16 hours of in-home respite to allow family members to attend to medical appointments, run errands, or attend family support group meetings. The center also provides time-limited round the clock emergency care in the home in situations where the family caregiver must be away from home or is ill and unable to continue providing care.
- The center offers *legal and financial guidance* to help caregivers deal with issues pertaining to incompetency and surrogate decisionmaking, property, planning for long-term care costs, etc. Funding for legal and financial assistance was initially provided through the center's Alzheimer's Legal Support Project, a demonstration project funded by the Administration on Aging.

SOURCES: R. Goldstein, director, New York City Alzheimer's Resource Center, New York, NY, personal communication, June 1988; New York City Department for the Aging, "Caregiver Training and Support Resource Center," proposal for the New York State Office for the Aging, New York, NY, 1988; New York City Department for the Aging and the Brookdale Foundation, *Agendas for Action: The Aging Network Responds to Alzheimer's Disease*, compiled and written by F. Tanner (New York, NY: August 1986); and New York City Department for the Aging Alzheimer's Resource Center and the New York City Chapter of the Alzheimer's Association, *Alzheimer's Disease: Where To Go for Help in New York City* (New York, NY: November 1987).

country. Currently, the National Association of State Units on Aging is trying to create a national access system that would connect the information and referral programs of aging network agencies across the country (577). This system, called "Elderlink," was initiated in Illinois in 1989 (148). Of the 49 State units on aging that responded to a survey conducted by the National Association of State Units on Aging, 16 State units said that AAAs would be the most appropriate referral point for the national access

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system for information and referrals; 9 State units said that a single statewide telephone number would be the most appropriate referral point for the access system; 7 said that a combination of AAAs and a single statewide telephone number would be the most appropriate referral point; 13 advocated options that involved other community agencies; and 4 did not specify an opinion (577).

This OTA report identifies visibility in the community as an important criterion for designating the agencies that should constitute a system to link people with dementia to services. Visibility in the community is particularly important for the information and referral component of a linking system because families and others must initiate contacts with information and referral sources themselves. Because the specific names of AAAs vary and because some AAAs are located within multipurpose agencies, some families and others may not be aware of the AAA as a source of help in finding services.

The 1987 study of 25 AAAs by the Office of the Inspector General of the U.S. Department of Health and Human Services concluded that within their service areas, the 25 AAAs were generally better known to service providers than to elderly people (853). The vast majority (nearly 90 percent) of 179 local service providers contacted for the Inspector General's study knew the local AAA existed, but only about half of the 122 elderly people interviewed for the study knew of the local AAA.

One commentator has noted that although some elderly people are aware of their local AAA, many millions of older people and their families do not know that AAAs exist or do not know the names of the agencies, where they are located, or how to get in touch with them (68). On the other hand, people may be more aware of the AAA in their area than of some of the other categories of agencies discussed in this chapter.

Case Management

Some AAAs provide case management directly; some AAAs contract with other agencies to provide case management; and some AAAs do neither. A 1987 survey of 144 AAAs conducted by the National Association of AAAs found that 60 of these AAAs (about 40 percent) provided case management directly (462). According to the association, as of 1989, some AAAs in more than half of all States were providing case management—also called "care management" or "care coordination"—and additional AAAs were planning to offer it (568). Box 8-B describes the care management program of the Region IV AAA in St. Joseph, Michigan. The care management program, which began as a pilot project in a three-county area of the State in 1983, has since been expanded to other parts of the State.

Despite the significant number of AAAs that are providing case management, there is considerable controversy about whether AAAs *should* provide case management. In connection with their planning function, AAAs are mandated by the Older Americans Act to "conduct efforts to facilitate the coordination of community-based, long-term care services . . . designed to emphasize the development of client-centered case management as a component of such services" (818). Thus, AAAs are mandated to encourage the development of case management in the community, but there is no mandate in the act for AAAs to provide case management.

The Administration on Aging and some AAAs view case management as a "direct service" that AAAs are, and should be, prohibited from providing (627). Having AAAs provide case management, the Administration on Aging argues, could detract from AAAs' ability to plan and coordinate comprehensive and coordinated systems of community services for elderly people (853). In contrast, the National Association of AAAs and some AAAs consider case management an "administrative function" that AAAs are not prohibited from providing (568). The National Association of AAAs argues that case management is a function that complements AAAs' mandated functions of coordinating community services for elderly people and ensuring access to the services.

The director of the Region IV AAA in St. Joseph, Michigan (see box 8-B) refers to the view that providing case management detracts from an AAA's planning and coordinating functions as "a phantom issue" and argues that:

> Far from detracting, [providing case management] *enhances* the comprehensive planning process. The additional valuable data on the needs of frail persons give an AAA additional guidance in changing priorities and developing services. Since the inception of our case management activities, we

> have developed financial management services for those not needing full guardianship, funded respite care, focused on the development of housing alternatives, and devised formal training programs for agencies serving Alzheimer's victims and their families (170).

In the opinion of the National Association of AAAs, AAAs are an appropriate setting for case management for several reasons: 1) AAAs are already connected to a range of formal and informal service providers and systems; 2) AAAs generally do not provide services or, if they do provide services, they do not charge for them, and therefore they have no financial or other incentives to overuse services; and 3) AAAs are not in competition with other community service providers (568,627). With regard to the competition among community service providers, the director of the Region IV AAA in St. Joseph, Michigan (see box 8-B) points out:

> When our AAA launched its case management project, we pulled together as many service providers as we could find to inform them of our intentions. Almost every provider felt it could do a better job than we. We were, however, practically every agency's *second* choice because of the vested interest of their competitors (170).

Clearly, however, providing case management places AAAs in competition with other agencies and individuals that provide case management, including agencies that provide case management in conjunction with other services such as home health care.

Some AAAs that provide or contract for case management do so with Title III Older Americans Act funds, and some use public funds from other sources, such as State general revenues, Medicaid, and the Federal Social Services Block Grant (354, 587). In addition, some AAAs provide fee-for-service case management that is paid for by individual clients, and some AAAs have contracts with private companies to provide case management for their employees or, in the case of insurance companies, their policyholders. In 1987, for example, 11 AAAs in Washington State contracted with Blue Cross of Washington and Alaska to provide case management for holders of the company's long-term care insurance policies (416).

Very little information is available about the capability of AAA case managers to work with people with dementia. In the 1985 survey of the AAAs and other agencies in Massachusetts mentioned previously, 14 of the 24 responding agencies, all but two of which were AAAs, reported that they provided case management for people with Alzheimer's disease (756). Five of the 14 agencies reported that all of their case managers had special training about Alzheimer's disease, and 10 of the 14 agencies reported that their case management supervisors had special Alzheimer's training (typically received at workshops sponsored by the Alzheimer's Association).

An exploratory study conducted for OTA in 1988 involved interviews with case managers in five Pennsylvania AAAs to determine what they perceived to be the unique aspects of working with people with dementia and their families (934). The findings of the study, which are discussed at length in chapter 3, provide some insight into the difficulties involved in providing case management for individuals with dementia and the capability of case managers in those AAAs to work with individuals with dementia and their families.[6] On the basis of the interviews with these case managers, OTA's contractors concluded that some of the case managers dealt with clients with dementia and their families in very skillful ways. None of the case managers had received any special training for this ability, however (934).

Public Education

As discussed earlier, the results of the 1986 survey of AAAs and State units on aging conducted by the New York City Department for the Aging (605) and the 1987 mail survey of AAAs in Virginia (193) indicate that many AAAs have sponsored a variety of programs and developed or paid for the development of materials to educate the public about Alzheimer's disease, dementia, and services for people with dementia. Often agencies of various types conduct public education efforts on a one-shot basis, and it is unclear from the results of the surveys whether this is the case with the AAAs that responded to the two surveys.

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[6] A full report on this OTA contract is available from the National Technical Information Service in Springfield, VA (see app. A).

Box 8-B—The Care Management Program of the Region IV Area Agency on Aging in St. Joseph, Michigan

Michigan's Region IV area agency on aging (AAA) in St. Joseph, Michigan, operates a care (or case) management program for people of all ages who live in the AAA's three-county service area and are at risk of nursing home placement. The AAA's program began in 1983 as a case management program for people over age 60 who were at risk of nursing home placement and had exhausted all other community long-term care resources. In 1987, the program was expanded with funds from the Michigan Department of Social Services to include nursing home preadmission screening and case management for people of all ages who are eligible or potentially eligible for Medicaid-funded nursing home care.

Funding for the AAA's care management and screening program comes from both the Michigan Office of Services to the Aging, which is the State unit on aging, and from the Michigan Department of Social Services, which is the State Medicaid agency. Funds from the Office of Services to the Aging are used to provide case management and a variety of services for medically qualified clients who are over age 60. Funds from the Department of Social Services are used to provide case management and services for medically qualified clients of all ages who meet specified financial eligibility criteria. By using funding from whichever source accommodates the eligibility characteristics of a client, the program enables any person medically qualified for nursing home care to participate.

Potential clients are referred to the AAA's care management and screening program by various sources. About 30 percent of referrals come from hospitals and physicians; 20 percent from home health agencies; 20 percent from family and friends; and the rest from a variety of other sources. The AAA publicizes its program through the Alzheimer's Association and other community organizations, and about 20 percent of its clients are people with dementia.

Each client referral received on the phone is screened by an intake specialist. If the intake specialist believes that the person is at risk of nursing home placement, the intake specialist refers the person to the care management team for a comprehensive assessment. From November 1987 to November 1988, intake specialists interviewed 509 individuals; 395 of them were referred for a comprehensive assessment, and the rest were referred to service providers in the community.

The AAA's program has five care management teams, each consisting of a social worker and a registered nurse. These teams conduct comprehensive assessments of the health status, functional ability, and informal support system of people referred to them. After conducting this assessment, the team discusses care options with the client

AAAs that sponsor public education programs or develop materials about dementia and services for people with dementia often do so in collaboration with an Alzheimer's Association chapter or other voluntary organizations that assist people with dementia and their families. On their own or in collaboration with these other organizations, some AAAs have published and disseminated service directories and brochures, books, videotapes, newsletters, and other educational materials about Alzheimer's disease (605). Some AAAs have sponsored public service announcements on the radio, television, or in newspapers to inform the public about Alzheimer's disease, and some have provided speakers for community programs about dementia. OTA is not aware of any data on the percent of AAAs that have conducted any of these activities.

The Geriatric Authority of Holyoke, Massachusetts operates an Alzheimer's Resource and Referral Center with Older Americans Act funds provided by the local AAA, Holyoke/Chicopee Regional Senior Services. The Alzheimer's Resource and Referral Center maintains a resource library with books, videotapes, and training materials related to Alzheimer's disease. In addition, the center offers educational programs, publishes a monthly newsletter about Alzheimer's disease and services for people with dementia, and conducts nursing home tours for caregivers who are looking for a nursing home for a person with dementia. The center also provides support groups for caregivers and a support group for patients who are in the early stages of their disease. The center's director regularly telephones some family caregivers who are unable to attend support group meetings to provide emotional support and reduce the caregivers' sense of isolation (494).

Outreach

In conjunction with their planning function, AAAs are mandated by the Older Americans Act to:

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and family members and develops a plan of care. If a client is capable of remaining in the community with in-home supportive services, the care managers determine which services are needed and arrange for their provision either by agencies that have cooperative, nonfinancial agreements with the AAA's program or by providers who bid competitively to serve the program's clientele. Each care management team handles a caseload of about 40 clients.

Care managers may purchase services for clients only if no other payment options (e.g., Medicare or private resources) exist. To resolve service payment issues, care managers rely on the program's consultation staff, consisting of an eligibility specialist and nurse consultant. For clients who cannot afford to pay privately for services and initially are not eligible for Medicaid, the program provides financial management services. If it is determined that Medicaid and other payment options are not available for a client, care managers may pay up to $975 per month for services for the client. The program uses a system of "priority groups" based on need for services and ability to pay for them to ensure that care managers purchase services for clients in the greatest need.

To make sure that clients and caregivers are satisfied with the services they are receiving and to monitor any changes in their situation that may necessitate a change in the plan of care, a member of a care management team makes regular followup visits at least every 3 months to the client's home. If the situation warrants it (e.g., a client's condition is unstable), followup is more frequent. Care managers use verbal reports from clients and caregivers to monitor the quality of services provided (529).

In fiscal year 1988, the Region IV AAA's care management and screening program provided comprehensive assessments to 319 clients, at an average cost per client of $100, and care management services to 386 clients, at an average cost per client of $895. These services were funded with $199,200 from the Michigan Department of Social Services and $186,000 from the Michigan Office of Services to the Aging.

In addition, the program directly purchased services costing $42,794 which includes $37,284 to provide 88 clients with long-term services such as personal care, home-delivered meals, homemaker, respite, financial management, and counseling services, and $5,510 to provide 36 clients with one-time or short-term services such as environmental aids (e.g., grab bars, safety rails), medications or personal hygiene items (e.g., adult diapers), and immediate response services (e.g., ambulance trips).

SOURCES: L.B. Kellogg, associate director, Region IV AAA, Inc., St. Joseph, MI, personal communication, Nov. 2, 1989; and Michigan Region IV Area Agency on Aging, Inc., "Michigan Department of Social Services: Preadmission Screening Program Annual Report," St. Joseph, MI, Feb. 15, 1989.

> . . . assure the use of outreach efforts that will identify individuals eligible for assistance under the act, with special emphasis on rural elderly, older individuals who have greatest economic need (with particular attention to low-income minority individuals), older individuals who have greatest social need (with particular attention to low-income minority individuals), and older individuals with severe disabilities, and inform such individuals of the availability of such assistance (818).

In addition, the Act authorizes the use of Title III funds for "services designed to encourage and assist older individuals to use the facilities and services available to them" (818).

The extent to which AAAs ensure the provision of outreach and the mechanisms by which they do so vary. In some areas, senior centers that have been designated by local AAAs as focal points for service delivery attempt to seek out and serve isolated elderly people (240). In addition, some AAAs provide outreach through door-to-door canvassing to identify homebound or isolated people in need of services (575). OTA is unaware of any data on the extent of these activities. One commentator has concluded, however, that many AAAs serve a disproportionate number of people who are already connected to the formal service system (240). Several individuals have told OTA that demented elderly people without family caregivers are unlikely to come to the attention of most AAAs unless they are referred by another community agency (69,261).

An increasing number of AAAs are becoming involved in various ways in "gatekeeper" programs that could help them identify isolated people with dementia and isolated caregivers. As discussed in chapter 3, gatekeeper programs recruit individuals such as utility meter readers and mail carriers who come into contact with many people in the course of their regular daily activities and train them to identify elderly people who may need assistance and refer such people to a central agency. The first

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gatekeeper program in this country was established in 1978 by a community mental health center in Spokane, Washington, with funding and technical assistance from the Eastern Washington AAA.[7] The New York City Alzheimer's Resource Center (see box 8-A) receives referrals from a gatekeeper program sponsored by a local utility company (261).

A 1988 survey of AAAs, State units on aging, and State public utility commissions found that 146 AAAs in 46 States and the District of Columbia were involved in gatekeeper programs, most of which had been developed during 1987-88 (320). The "gatekeepers" for these programs are employees of 164 companies or organizations, including electric, gas, telephone, and water companies, post offices, social service organizations, pharmacies, groceries, banks, libraries, and cable television companies.

According to the results of the 1988 survey, AAAs play a variety of different roles in gatekeeper programs, including helping to start up the programs, developing training programs for the gatekeepers, training the company trainers, training the actual gatekeepers, training agency personnel to receive referrals from the gatekeepers, keeping records of referrals, and monitoring the program (320). Referrals from the gatekeepers generally are received either by the AAA or by an information and referral agency. The AAAs that were involved in the programs identified by the 1988 survey reported receiving an average of 4 to 5 referrals a month. Many of the programs were so new at the time of the survey, however, that they could not provide any information about average number of referrals.

It is unclear to what extent these gatekeeper programs will help AAAs identify isolated people with dementia and isolated caregivers. Many of the programs are run by utility companies, and the primary focus in some of those programs is bill payment problems (320). Nevertheless, the programs provide a mechanism by which some people who need assistance, but would not contact an AAA or any other agency on their own, can be referred for help.

Role in Allocating Services and Funding

AAAs allocate services that are paid for with Title III Older Americans Act funds. Eligibility for these services is generally limited to people over age 60. As noted earlier, AAAs are prohibited from using means testing to determine elderly people's eligibility for services funded with Title III money, and they may not charge fees for these services (although they may request voluntary contributions).

Many AAAs also allocate services paid for by other public and private funds. The Region IV AAA in St. Joseph, Michigan (see box 8-B) allocates services paid for by Medicaid and by Michigan's Alternate Care Program, a program funded entirely with State money. Likewise, the New York City Alzheimer's Resource Center (see box 8-A) allocates services paid for with city funds and private foundation grants, in addition to other sources. When an AAA allocates services paid for with public or private funds other than Federal Older Americans Act funds, it does so on the basis of the eligibility criteria set by those other funding sources —criteria that may be very different from the eligibility criteria for services paid for with Older Americans Act funds.

Probably the best examples of AAAs allocating services on the basis of eligibility criteria that are different from the eligibility criteria for services paid for with Older Americans Act funds are the AAAs that have been designated by States to administer State nursing home preadmission screening programs and Medicaid 2176 Home and Community-Based Waiver programs. In administering these programs, some of which are discussed in chapter 7, AAAs use means testing and strict functional and medical criteria to determine people's eligibility for services. It is important to keep in mind that AAAs that administer these programs are operating not only as agencies mandated by Title III of the Older Americans Act, but also as public or private agencies that have many functions other than those mandated by the act.

Summary

As agencies that might be designated to constitute a national system to link people with dementia to services, AAAs offer many advantages:

- AAAs exist in every State.
- AAAs already have connections to many different agencies and individuals that provide services that may be needed for people with dementia.

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[7] The gatekeeper program in Spokane, Washington, is described in box 8-C in the following section of this chapter.

- Some AAAs provide information and referrals and case management for elderly people, including some people with dementia.
- Some AAAs have sponsored public education programs and developed or paid for the development of public education materials about Alzheimer's disease, dementia, and services for people with dementia.
- Some AAAs are involved in outreach programs that may help them to identify isolated people with dementia and isolated caregivers who would not contact the AAA or any other agency on their own.
- AAAs probably have more visibility in their communities than some of the other categories of agencies discussed in this chapter.
- AAAs are part of a nationwide network of agencies and therefore have the potential to serve long-distance caregivers who need help in locating and arranging services for an elderly person with dementia.

Despite these considerable advantages, there would be several drawbacks to designating AAAs as the basis for a national system to link people with dementia to services. The most important drawback relates to questions that have been raised about the capacity of AAAs to work effectively with people with dementia and their caregivers. As discussed in this section, OTA has heard complaints that some AAAs' resource lists are not accurate or comprehensive with respect to the services that may be needed for people with dementia, that some AAAs' staff are not informed about dementia or services for people with dementia, and that some AAAs' staff are not responsive to the needs of people with dementia. OTA does not know how widespread any of these problems are. AAAs have many mandated functions and serve many different client groups, so it is to be expected that some AAA staff members are not knowledgeable about dementia or services for people with dementia. Moreover, this section has cited numerous ways in which some AAAs are serving people with dementia effectively. Nevertheless, the perception of family caregivers, Alzheimer's advocates, and others that AAAs are uninformed about dementia and/or unresponsive to people with dementia and their caregivers is a major drawback to designating AAAs to constitute a linking system for people with dementia.

A second drawback to designating AAAs as the basis for a national system to link people with dementia to services is the diversity of AAAs. What may appear from the Federal level and in the context of the Older Americans Act as 670 agencies with similar functions are, in fact, 670 agencies that differ from each other in virtually all respects except that they receive Title III Older Americans Act funds. Some AAAs are essentially planning agencies that provide few, if any, programs for individuals. Without significant changes, those AAAs could not function effectively as linking agencies for people with dementia. Moreover, many of the most impressive programs provided by AAAs for people with dementia are programs that are paid for primarily by public funds other than Older Americans Act funds or by private funds. That one AAA or AAAs in one State provide such programs does not indicate that other AAAs in other States could also do so, because the other AAAs may not have access to funding for the programs.

A third drawback to designating AAAs as the basis for a national linking system for people with dementia is that services and programs paid for with Older Americans Act funds are generally limited to people over age 60, whereas some people with dementia are under age 60. This problem would appear to be easily resolved by legislation that lowered the age limit generally or for certain programs.

A final drawback is the lack of outreach in some AAAs. People with dementia who live alone and have no informal caregiver are unlikely to contact an AAA or any other agency on their own. If AAAs were designated to establish a national system to link people with dementia to services, effective outreach methods would have to be implemented by all AAAS.

Lastly, it should be noted that although the analysis in this section has focused primarily on AAAs, the discussion in chapter 7 about State programs and systems that link people to services shows that State units on aging are generally involved in and often initiate aging network programs that link elderly people to services. If AAAs were designated to establish a national system to link people with dementia to services, State units on aging should be included in that designation.

COMMUNITY MENTAL HEALTH CENTERS

Community mental health centers (CMHCs) are local agencies that provide mental health services for people of all ages who have mental and emotional problems. CMHC services include diagnosis and assessment of mental health problems; psychotherapy; individual, group, marital, and family counseling; pharmacological treatment for mental health problems; and other mental health services. All CMHCs provide mental health services on an outpatient basis, and some CMHCs also offer inpatient mental health services.

There is no generally accepted figure for the number of CMHCs in the United States, in part, because of a lack of agreement about which agencies should be counted as CMHCs. The 1987 National Registry of Community Mental Health Services, published by the National Council of Community Mental Health Centers, listed 1,800 agencies that provided community mental health services, and an additional 2,800 ''satellite'' service locations associated with the 1,800 agencies (583). The 1,800 agencies and their satellite locations existed in all 50 States, the District of Columbia, Puerto Rico, Guam, and the Virgin Islands. By 1990, the Council's list of agencies that provide community mental health services had grown to 2,300 agencies, not including satellite locations (207). The council believes that its 1990 list probably includes almost all agencies that could be considered CMHCs (207).

OTA has included CMHCs in its analysis of agencies that might constitute a national system to link people with dementia to services for several reasons. One reason is that many CMHCs provide public education, information and referral, case management, and outreach for mentally ill people, and at least a few CMHCs provide these linking functions for people with dementia. In addition, CMHCs' expertise in assessing and treating mental, emotional, and behavioral problems is relevant to identifying the service needs of people with dementia and their caregivers and linking them to appropriate services. Although the diseases that cause dementia are physical conditions, their manifestations often include mental, emotional, and behavioral problems, and these problems are frequently the most difficult aspect of a patient's illness for families and others to manage (681,705). If the problems are assessed and treated effectively, a patient's overall functioning may be improved. Even if no fundamental changes can be made in a patient's functioning, the family or other caregivers can be taught ways of managing the patient's problems so that the burden of caregiving is reduced. In either case, the patient's service needs are likely to be changed and decreased. The expertise of CMHCs' staff in assessing and treating emotional problems may also benefit people with dementia and caregivers who have feelings and perceptions that make them reluctant to use needed services.[8]

Overview of the Agencies

Outpatient mental health services have been available on a limited basis from various kinds of community agencies and from individual psychiatrists, psychologists, and other mental health professionals for a long time. Federal support for ''community mental health centers'' was initiated in 1963 with passage of the Community Mental Health Services Act (Title II of Public Law 88-164) that authorized Federal grants to local groups to establish CMHCs (766,808). The 1963 act funded CMHC construction and required CMHCs to provide five types of mental health services: 1) inpatient services, 2) outpatient services, 3) partial (day or night) hospitalization, 4) emergency services, and 5) consultation and education (766). In subsequent years, Congress added funds for planning and staffing and expanded the types of mental health services CMHCs were required to provide.

In 1981, Federal funding for the CMHC program and nine other programs was consolidated into a block grant—the Alcohol, Drug Abuse, and Mental Health Services (ADMS) block grant (766,808). States were given the authority, within certain legislated limits, to set priorities for the use of the block grant funds and to allocate the funds. In order to receive Federal ADMS block grant funds, CMHCs were required to provide five types of mental health services: 1) outpatient services, 2) 24-hour emergency care, 3) day treatment or partial hospitalization, 4) screening of potential State institution residents, and 5) consultation and education. Inpatient services were not included.

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[8] The kinds of feelings and perceptions of people with dementia and their caregivers that make them reluctant to use needed services are discussed in ch. 3.

At the Federal level, the ADMS block grant is administered by the Alcohol, Drug Abuse, and Mental Health Administration in the U.S. Department of Health and Human Services. This agency has certain oversight responsibilities and assesses each State's compliance with legislative mandates through the block grant application process, annual reports, audits, and compliance reviews. At the State level, the ADMS block grant is administered by a designated State agency—usually the State department of health, human services, or mental health.

By 1981, when the ADMS block grant was established, more than 700 CMHCs had received Federal funds under the Community Mental Health Services Act of 1963 (625,766,806,808), and about 500 of these CMHCs were still receiving Federal funds under the act (806). For some years after the establishment of the ADMS block grant, States were required to allocate some of their block grant funds to those CMHCs that received Federal funds under the 1963 act in 1981, and would have been eligible to receive funds under the act in subsequent years. This requirement is no longer in effect, but some, and perhaps many, CMHCs that were funded under the 1963 act do receive ADMS block grant funds (207). The number of such agencies is not known because the data system that was in place under the 1963 act to collect information about CMHCs was discontinued when the block grant was established, and no alternate system was created to collect the information.

In addition to CMHCs that were funded under the Community Mental Health Services Act of 1963, there are many other agencies that provide community mental health services, but never received Federal funding under the 1963 act. As noted earlier, the National Council of Community Mental Health Centers has a list of 2,300 agencies that provide community mental health services. That number includes agencies that were funded under the 1963 act and agencies that were not. Some agencies that provide community mental health services but were not funded under the 1963 act currently receive ADMS block grant funds, but the number of such agencies is not known (207).

Although CMHCs are sometimes discussed as if they were a clearly defined group of agencies, there is no agreement about precisely which agencies should be considered CMHCs. The term "community mental health center" is a generic one that was used in the 1963 act, but many agencies that provide community mental health services are not called "community mental health centers" and have a variety of other names. The agencies that received funding under the Community Mental Health Services Act of 1963 can be identified and are identified, for example, in the 1987 National Registry of Community Mental Health Centers (583). The characteristic that made those agencies a clearly defined group—receipt of Federal funds under the 1963 act—ceased to exist almost a decade ago. Agencies that provide community mental health services but did not receive funding under the 1963 act, have never been a clearly defined group.

In the national inventory of mental health organizations conducted in 1986 by the Alcohol, Drug Abuse, and Mental Health Administration, agencies that provide community mental health services were subsumed under four categories:

1. freestanding psychiatric outpatient clinics (of which there were 780),
2. freestanding psychiatric day/night (partial hospitalization) organizations (of which there were 97),
3. multiservice mental health organizations (of which there were 1,363), and
4. general hospitals with separate psychiatric outpatient services (of which there were 1,354) (489).

These four categories included both agencies that did and did not receive funding under the 1963 act.

OTA is not aware of any research on agencies that provide community mental health services that compares agencies that received funding under the 1963 act and agencies that did not. One commentator believes that there are probably very few differences between the two groups of agencies, but that agencies that received funding under the 1963 act may tend to be larger, to provide more comprehensive mental health services, and to be more focused on caring for the indigent than agencies that did not receive funding under the act (207). If Congress chose to designate CMHCs to constitute a national system to link people with dementia to services and if, as has been suggested, the two groups of agencies are quite similar, Congress would probably want to include both groups of agencies in the system. It should be recognized, however, that determining exactly which agencies are CMHCs for this purpose may be difficult.

More importantly, the mechanism by which the Federal Government could designate CMHCs to constitute a national linking system for people with dementia is unclear. States determine which agencies receive ADMS block grant funds; thus block grant funding does not create a direct link between the Federal Government and CMHCs. Moreover, some agencies that provide community mental health services and could be part of a national linking system may not receive ADMS block grant funds, and there is no obvious connection between the Federal Government and those agencies. Lastly, States operate many mental health facilities, including outpatient mental health clinics, some of which are on the grounds of State mental hospitals (207,719). These clinics are considered CMHCs by some States and are included in some lists of CMHCs. As State agencies, their functions are determined by State government; whether they could be part of a national linking system for people with dementia would be the decision of each State.

In fiscal year 1989, $246 million of the Federal appropriation for the ADMS block grant was targeted for mental health (520), and much of this amount funded CMHCs. ADMS block grant funds make up only 6 percent or less of the budget of the average CMHC, however (207,441,489,584,719). A 1987 survey of agencies that are members of the National Council of Community Mental Health Centers found that in addition to the 6 percent from the ADMS block grant, the average CMHC received 43 percent of its budget from State government, 13 percent from local government, 11 percent from Medicaid, 9 percent from client fees, 8 percent from private insurers, and 11 percent from other sources, such as the Social Services Block Grant, charitable contributions, and Medicare (584).[9]

Who Is Served

CMHCs provide mental health services for people of all ages. CMHCs that receive ADMS block grant funds are specifically required to serve seriously mentally ill adults, emotionally disturbed children, mentally ill elderly people, and other underserved populations in their service areas, regardless of the individuals' ability to pay for the services, current or past health condition, age, handicap, race, or sex.

In the years since the establishment of the ADMS block grant, the influence of the Federal Government has given way to the expanded role of State governments in planning and directing community mental health services, and CMHCs have modified their programs and services to reflect State priorities. Most States give highest priority to serving seriously mentally ill people, and CMHCs have increasingly targeted their programs to serve this client population (370,441,585,719). The term "seriously mentally ill" (previously "chronically mentally ill") usually refers to adults with a diagnosis of schizophrenia, a major affective disorder, psychosis, or a personality disorder, and a recent history of psychiatric care that required more than voluntary outpatient treatment (585). The term "seriously mentally ill" is not usually used to refer to people with Alzheimer's disease or other diseases that cause dementia.

The extent to which CMHCs serve people with dementia is not known. Data from the national inventory of mental health organizations conducted in 1986 by the Alcohol, Drug Abuse, and Mental Health Administration showed that among the clients of the four types of agencies included in the survey (freestanding psychiatric outpatient clinics, freestanding psychiatric day/night organizations, multiservice mental health organizations, and general hospitals with separate psychiatric outpatient services), only 4 percent had a diagnosis of organic brain syndrome (489), a diagnosis that often includes Alzheimer's disease and other diseases that cause dementia. Since CMHCs were subsumed under these four categories of agencies, the data suggest that CMHCs were serving very few people with dementia.

A 1984 survey of agencies that were members of the National Council of Community Mental Health Centers found that one-third of the 281 responding agencies reported that they had special services for people with Alzheimer's disease and their families. How representative these findings were for all CMHCs is not known. In the 6 years since the data were collected, awareness of Alzheimer's disease and the special service needs of people with Alzheimer's and other dementing diseases has increased greatly in this country, and more CMHCs may have special services for people with dementia now than in 1984. On the other hand, the fact that a CMHC has special services for people with Alzheimer's disease says almost nothing about how many people with Alzheimer's or other dementing diseases the agency serves.

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[9] ADMS block grant funds are a very small part of all funds allocated by States for mental health services—less than 3 percent in fiscal year 1986 (573). Most funds allocated by States for mental health services are used to pay for inpatient services.

The 1984 survey found that agencies that reported that they had special services for elderly people were much more likely than other agencies to also report having special services for people with Alzheimer's disease (458). Although OTA is not aware of any research to this effect, it is logical that there could also be an association between the number of elderly people served by agencies that provide community mental health services and the number of people with dementia served by these agencies, especially since the great majority of people with dementia are elderly. If the latter association exists, then people with dementia are probably underserved by CMHCs since CMHCs have historically underserved elderly people (6,7,419,458,766,806).

Beginning in 1975, Congress has repeatedly mandated more services for elderly people through CMHCs, and some progress has been made in increasing the number of elderly people served by these agencies (6,7). Since the establishment of the ADMS block grant, however, CMHCs' emphasis on serving seriously mentally ill people has resulted in fewer services for other client groups, including elderly people (6,7,441,458,585,806,808). OTA is not aware of any current national data on the number of elderly people served by CMHCs, but a 1987 survey of 335 CMHCs by the National Council of Community Mental Health Centers found that elderly people constituted only 8 percent of the agencies' clientele (584), even though elderly people make up 12 percent of the U.S. population.

Many reasons have been cited to explain the underrepresentation of elderly people in the clientele of agencies that provide community mental health services. These reasons include:

- negative attitudes of mental health professionals about elderly people and their potential to benefit from mental health treatment,
- limitations on reimbursement for mental health services through Medicare,
- lack of transportation,
- lack of awareness of mental health services among elderly people, and
- resistance to the use of mental health services among elderly people (238,419,445,451,692, 766,808,889).

Most important for this assessment is the fact that some, and perhaps many, elderly people and some younger people perceive a stigma associated with the use of mental health services (272,419,445,889).

Notwithstanding these problems, a few CMHCs have been very successful in developing comprehensive elderly service programs that target and serve elderly people with dementia (97,419,688). One such program, developed in the State of Washington by the Spokane CMHC with support from the Eastern Washington AAA, is described in box 8-C. This program provides public education about mental health problems in elderly people, including mental and emotional problems associated with dementia; information and referrals for elderly people with mild cognitive impairments; case management for elderly people with more serious mental problems; and outreach to identify elderly people who need services, but are not willing or able to contact service providers on their own (688,689).

Another program operated by a CMHC in Ventura County, California, also serves elderly people with dementia and provides all four functions that OTA concludes are essential to link people with dementia to appropriate services: public education, information and referral, case management, and outreach. That program is described in detail in a recently published book, *Outreach With the Elderly: Community Education, Assessment, and Therapy* (418).

Linking Functions

Information and Referral

CMHCs provide information and referrals for their own clients. CMHCs are also capable of providing information and referrals for the general public, but the extent to which they do so is not known. Likewise, CMHCs are capable of providing information and referrals for long-distance caregivers who need help locating services for a relative who lives in the CMHCs' service area, but the number of long-distance caregivers who are served by CMHCs is not known.

Box 8-C—The Spokane Community Mental Health Center's Elderly Services Program, Spokane, Washington

In 1978, the Spokane Community Mental Health Center (CMHC) established an Elderly Services Program to provide mental health and other services for elderly people, especially frail, vulnerable, and moderately to severely impaired elderly people. The program receives 60 percent of its funding from the Eastern Washington AAA (Older Americans Act and Washington State aging funds). Other program funds come from the State mental health grant-in-aid program, the ADMS block grant, and the National Institute on Drug Abuse.

The Spokane CMHC's Elderly Services Program has two components:

- a telephone information and referral component for elderly people who have mild psychiatric and/or cognitive impairments and who have a caregiver or other support system that is willing and able to act on their behalf; and
- a multidisciplinary assessment, treatment, and case management component that offers elderly people believed to be at high risk of institutionalization a comprehensive in-home assessment, a variety of preventive, rehabilitative and supportive services, and case management.

The information and referral component is staffed by three telephone screeners. The case management component is staffed by a program manager and 5 multidisciplinary teams which include 5 team leaders (4 are nurses), 15 case managers, 1 psychiatrist (36 hours/week), and resident physicians.

Elderly people are sometimes referred to the case management program by their families. Other referrals come from volunteer "gatekeepers." Volunteer gatekeepers are individuals who interact with many people in the course of their regular activities—e.g., mail carriers, meter readers, and other utility workers; property appraisers; apartment and mobile home court managers; fuel oil dealers; employees of police, ambulance, and fire departments; grocery clerks; and pharmacists—and are specially trained to identify individuals who are confused, ill, or otherwise at risk. Training for gatekeepers is provided by the CMHC in cooperation with the corporations and businesses that employ the volunteers.

In 1987, gatekeeper referrals accounted for 37 percent of all clients admitted to the Elderly Services Program's case management program. Gatekeepers' outreach efforts were especially useful in identifying demented elderly people living alone. In 1987, 46 percent of the demented elderly people living alone who were referred to the program were referred by the gatekeepers.

The comprehensive in-home assessment that is given to each elderly person referred to the case management program is coordinated by a case manager who is accompanied on home visits by members of the multidisciplinary team. Following the assessment, the team develops a detailed plan of care. This plan seeks to make use of the potential of family and other support systems, and family conferences are held when needed. Caregiver support groups are also available.

The Spokane Elderly Services Program can deliver a variety of preventive, supportive, and rehabilitative in-home services via 14 agencies with which it has written agreements. Most of these agencies are AAA-funded. The most frequently used services are homemaker/chore services, visiting nurses and nurse aides, adult day health care, home-delivered meals, and respite. The Elderly Services Program is dependent on these other agencies to implement much of the treatment plan, and all agencies are involved in weekly case staffing meetings. The Elderly Services Program also provides at least 20 hours of training for the service providers (e.g., chore workers) on topics such as dementia and depression.

The Spokane CMHC's Elderly Services Program has been very successful in reaching elderly people. Whereas clients over age 60 represent between 4 to 8 percent of the CMHC population nationally, the Elderly Services Program's clients account for 22 percent of the Spokane CMHC's client population. Minority elders, who constitute only 2 percent of Spokane's elderly population, make up 6 percent of the case management program.

SOURCE: R. Raschko, "Spokane Community Mental Health Center Elderly Services," unpublished mimeo, Spokane Community Mental Health Center, Spokane, WA, May 25, 1988.

Some CMCHs provide referrals to all kinds of health care, long-term care, social, and other services, as well as to mental health services (97,419,688). Anecdotal evidence suggests that other CMHCs only provide referrals to mental health services (746).

Very little information is available about whether CMHCs generally have lists of community services to which they refer people, and if so, how they obtain the lists. One OTA panelist believes that some CMHCs generate their own resource lists and that other CMHCs use resource lists from a local United Way information and referral program, an AAA, or another source (689).

Case Management

The Community Mental Health Center Amendments of 1975 required CMHCs to provide case management for their elderly clients (766), but until the establishment of the ADMS block grant in 1981, CMHCs provided relatively little case management. Since then, most CMHCs have increased the case management they provide (370,441). One study of 54 CMHCs in 15 States found that in the 3 years after the establishment of the ADMS block grant:

> Most centers reported substantial improvements in their case management programs. Examples include conducting better assessments, more interagency collaboration, greater cooperation among staff from different services, more coordination, closer monitoring, specific staff assignments, more home visits and work with families, and better liaison with hospitals. Along with expanded services, most centers reported increased staff time devoted to case management, and in some States, increased funding as well (441).

CMHCs provide case management primarily for people with serious mental illness (207,370,441, 466,585). According to one source, the majority of CMHC clients who receive case management are either young adults or previously deinstitutionalized adults—many of who are now in their forties (207). A 1987 membership survey by the National Council of Community Mental Health Centers found that 86 percent of 595 responding CMHCs provided case management for their clients with serious mental illness (585).

The percentage of CMHCs that provide case management for people with dementia is not known but is probably small, given the targeting of most CMHCs' case management to people with serious mental illness. An official from one State has told OTA he believes that the case management technology used by CMHCs in his State for seriously mentally ill people could be adapted to serve people with dementia, but that the CMHCs' case management programs would have to be greatly expanded to serve the additional clients (466). OTA is aware of several CMHCs, however, that provide case management for many people with dementia (97, 419,688). One example is the CMHC in Spokane, Washington, that is described in box 8-C.

CMHCs vary with respect to the personnel they use to provide case management. Some, and perhaps many, CMHCs use a multidisciplinary team to provide the initial client assessment and care plan, and some CMHCs include a psychiatrist and/or a psychologist on the team.[10] Social workers, nurses, and psychologists provide ongoing case management in some CMHCs, but most CMHCs probably use personnel without these credentials. According to one source, many CMHCs assign the lowest ranking personnel with limited training and experience to provide case management for people with serious mental illness (523). To address this problem, one State, Rhode Island, has developed a voluntary formal training and certification program for CMHC case managers (905).

Whether CMHCs can provide effective case management for people with dementia depends in part on whether they have a working relationship with other community agencies that furnish the kinds of services that may be needed by people with dementia. Beginning in 1975, CMHCs were required by the 1975 amendments to the Community Mental Health Services Act of 1963 to coordinate their services with the services of other health care and social services agencies (766). In 1981, the law establishing the ADMS block grant reemphasized the need for CMHCs to coordinate services with other agencies.

Although some CMHCs have developed strong working relationships with other community agencies, many CMHCs have not (6,7,203,418,451). A 1983 survey of 233 CMHCs found almost no coordination and little routine interaction between CMHCs and AAAs (6). A followup survey 2 years later indicated that interactions between these types of agencies had increased, and 18 percent of the CMHCs reported having a formal agreement with the local AAA (7). Another survey in 1984 found that 23 percent of 281 responding CMHCs had a formal agreement with an AAA, and 66 percent had an informal affiliation (451). Interestingly, this survey found that CMHCs that were affiliated with AAAs—whether through formal or informal agreements—were twice as likely as other CMHCs to provide special services for people with Alzheimer's disease, respite care, and family support services.

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[10] CMHCs also use psychiatrists to make initial diagnoses, and some use psychologists to provide testing and other information needed for diagnosis.

Public Education

The Community Mental Health Services Act of 1963 and the law that established the ADMS block grant required CMHCs to provide "consultation and education" services. In response to a 1987 survey of 335 agencies that are members of the National Council of Community Mental Health Centers, 89 percent of the agencies reported that they were providing such services (584). Although no data are available, it is likely that many CMHCs provide public education programs and materials as part of their consultation and education services. The programs and materials may not pertain to dementia, however.

Some CMHCs that have special programs for elderly people provide public education programs and materials about dementia and about services for people with dementia (418,689). These programs and materials include community meetings, workshops, public service advertisements, brochures, and other printed materials. Some experts believe that vigorous public education efforts are essential in overcoming the stigma associated by some people with mental health services and that such efforts can be successful in getting elderly people, including people with dementia, and their caregivers to use the services provided by a CMHC (95,418).

Outreach

People with serious mental illnesses often are unable or unwilling to contact service providers on their own. For this reason, many CMHCs have developed outreach programs (585), but most of these programs probably do not target people with dementia.

The director of elderly services at the CMHC in Spokane, Washington, maintains that outreach is essential to serving demented elderly people who live alone (688). Some CMHCs that have special programs for elderly people have outreach programs that target these people. The Spokane CMHC's "gatekeeper" program (see box 8-C) is particularly effective in reaching demented elderly people who live alone; in 1987, 46 percent of the demented people living alone who were referred to the Spokane CMHC program were referred by the volunteer "gatekeepers."

ELDERLY SERVICES
INFORMATION & ASSISTANCE LINE
458-7450
COMMUNITY MENTAL HEALTH CENTER

Photo credit: Bill Adams, Northwest Images

The Eastern Washington Area Agency on Aging recently sponsored a public education campaign to inform people about the telephone information and referral program of the Community Mental Health Center in Spokane, Washington. Billboards like the one pictured here were displayed in early 1990 and are scheduled for use again in the fall of 1990.

Another CMHC serving two rural counties in Iowa also has a gatekeeper program that has been effective in identifying elderly people with dementia who need services but are unwilling or unable to contact service providers on their own (97,763). The gatekeeper program uses mail carriers, utility workers, and others to refer elderly individuals who needed assistance to an outreach team from the CMHC; the team then contacts the individuals, evaluates their service needs, refers them for medical and social services, and provides ongoing mental health services in the home, if needed.

Role in Allocating Services and Funding

CMHCs generally do not allocate services or funding for services other than those they provide.

Summary

As agencies that might be designated to constitute a national system to link people with dementia to services, CMHCs offer several advantages:

- There are more than 2,000 CMHCs nationwide.

- CMHCs typically employ a wide range of professionals, including psychiatrists, psychologists, nurses, social workers, and others who have expertise in the assessment and treatment of mental and emotional problems.
- CMHCs serve individuals of all ages.
- Many CMHCs have experience in providing case management.
- A few CMHCs provide public education, information and referral, case management, and outreach for people with dementia, thus suggesting that other CMHCs could also do so.

Despite these advantages, there are several important drawbacks to designating CMHCs as the basis of a system for linking people with dementia to services. The primary drawback is that many CMHCs serve relatively few people with dementia. CMHCs have historically underserved elderly people, and the great majority of people with dementia are elderly. Moreover, since the inception of the ADMS block grant, most CMHCs have focused increasingly on serving seriously mentally ill adults, a category that usually does not include people with dementia. Although these CMHCs provide information and referral, case management, and outreach for their clients who are seriously mentally ill, it would require a considerable change in direction and either a reallocation of agency resources or a significant increase in resources for these CMHCs to provide similar assistance for people with dementia. Obviously, a large-scale reallocation of CMHCs' resources from people who are seriously mentally ill to people with dementia would create a major gap in services for people who are seriously mentally ill.

A second drawback to designating CMHCs as the basis of a system for linking people with dementia to services is that some CMHCs do not have effective working relationships with other community agencies that provide the kinds of services that may be needed for people with dementia.

A third drawback is that CMHCs are not a clearly defined group of agencies that could be designated by the Federal Government to constitute the linking system nationwide. The generic term "community mental health center" is used to refer to agencies that received funding under the Community Mental Health Services Act of 1963—a group of agencies that can be identified precisely—and to other agencies that provide community mental health services but did not receive funding under the 1963 act—a group of agencies that cannot be identified precisely. Since there is no current source of direct Federal funding that is unique to either or both of these groups of agencies, it is unclear what mechanism the Federal Government could use to designate the agencies as the basis of a national linking system.

A final drawback is that some people with dementia and their families and other informal caregivers may not be willing to contact a CMHC for help in locating and arranging services because they perceive a stigma associated with mental health services. As indicated earlier, however, some experts believe that public education efforts by CMHCs can be successful in overcoming this stigma.

COMMUNITY HEALTH CENTERS

Community health centers (CHCs) are organizations that provide primary health care and other health-related services to individuals in a local community. Their clients include people who tend not to be adequately served by other health care providers: poor and low-income people, members of ethnic minority groups, and people who live in medically underserved areas. As of 1989, there were about 1,200 CHCs delivering care at more than 2,000 sites throughout the country.

OTA has included CHCs in its analysis of agencies that might constitute a national system to link people with dementia to services because CHCs reach population groups that often are not served by the other categories of agencies discussed in this chapter—notably, poor people and ethnic minorities.

Overview of the Agencies

Some CHCs receive Federal funding under Section 330 of the Public Health Service Act, which authorizes grants to public and private nonprofit organizations that provide primary health care to populations or areas that are "medically underserved."[11] To be eligible for Section 330 grants, CHCs must have a governing board with a majority of members who are users of the CHC's services.

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[11] A medically underserved population or area is one with a shortage of health care services. Among the factors the U.S. Department of Health and Human Services considers in determining whether an area or population is medically underserved are the accessibility of health services and people's ability to pay for health services (825).

Section 330 CHCs also must adjust their fees to their clients' ability to pay (578).

As of 1987, nearly 600 CHCs nationwide were receiving Section 330 grants (664). These CHCs provided health care services at approximately 1,600 different sites, including their primary location and satellite sites that ranged in size from full-service community clinics to outposts of single health professionals (664). At least some Section 330 CHCs exist in every State except Wyoming and in all U.S. territories (578). Because of their emphasis on serving medically underserved areas and populations, however, Section 330 CHCs typically are not uniformly distributed throughout a State.

Section 330 CHCs are required to provide the following primary health care services, either directly or through contracts or cooperative agreements with other agencies (825):

- physician and physician extender services,
- diagnostic laboratory and radiologic services,
- preventive health services,
- emergency medical services,
- transportation services,
- preventive dental services, and
- pharmaceutical services.

The decision about whether to provide other services—e.g., hospital, home health, mental health, dental, and vision services—rests with an individual CHC's governing board (693).

Section 330 CHCs supplement their Section 330 grants with funds from other sources. In fiscal year 1985, Section 330 CHCs received 48 percent of their total revenue from Federal grants, 16 percent from Medicaid, 5 percent from Medicare, 6 percent from other third party payers, 11 percent from patient fees, and 14 percent from State, local, and other sources (578). Federal Section 330 grants have been declining in recent years, so alternative sources of revenues are becoming increasingly important to CHCs.

In addition to Section 330 CHCs, there are an estimated 500 to 750 other CHCs that do not receive Section 330 grants (381,664). These CHCs do not receive Section 330 grants for a variety of reasons. Sometimes they do not apply for a grant because they either cannot meet or choose not to meet one or more Federal eligibility requirements—e.g., the requirement that more than half the members of the CHC's governing board be users of the CHC's services (381,664).

Very little information is available about CHCs that do not receive Section 330 grants. Anecdotal evidence suggests that Section 330 CHCs and other CHCs are similar in many ways, but that Section 330 CHCs tend to be larger and to provide a more comprehensive range of services (381,664). Some CHCs that do not receive Section 330 grants are affiliated with hospitals and are funded in part through the hospitals. Such CHCs also may receive funds from State and local governments, foundations, churches, and other philanthropic sources.

Many Section 330 CHCs, particularly the larger ones, have a full complement of health care professionals, including physicians, physician assistants, nurses, therapists, dentists, health educators, social workers, and others. No information is available about the number and type of staff in CHCs that do not receive Section 330 grants. Nor is it known how many CHCs of either type have staff who are knowledgeable about dementia. A 1986-87 study of 10 Section 330 CHCs identified by the La Jolla Management Corp. as having good programs for elderly people (693) found that only 1 of the physicians in the 10 CHCs had specialized geriatric training, although some of the other staff members in the 10 CHCs had attended geriatric training workshops and seminars. No information is available about the extent to which CHC staff members have specific training in dementia.

Who Is Served

In 1985, Section 330 CHCs served over 5 million individuals, many of whom might not have received health care services otherwise (578). Half of the CHC users resided in high-poverty urban communities, and half resided in rural areas. Sixty-five percent of the users were either black, Hispanic, or members of other ethnic minority groups.

Section 330 CHCs are intended to serve the poor, and 60 percent of the 5 million individuals who received health care services from Section 330 CHC's in 1985 had family incomes below the Federal poverty level; 85 percent had family incomes below 200 percent of the poverty level. Section 330 CHCs also serve some individuals who are able to pay for part or all of their care. Individuals whose family incomes are below the Federal poverty level are charged nominal fees, if any, for services. Individuals whose family income falls between 100 and 200 percent of the poverty level are charged a reduced fee based on their family income and family size. Individuals with family incomes above 200 percent of the poverty level are charged the full fee for CHC services.

The emphasis in many CHCs has been on providing care for mothers and children. In 1985, 45 percent of Section 330 CHCs' clients were children. Only 9 percent were people over age 65 (578).

The extent to which CHCs serve people with dementia is not known. As comprehensive health centers, Section 330 CHCs diagnose and treat people with a variety of conditions. In 1982, the most commonly observed diagnoses, in descending order, were vaginitis, otitis media, urinary tract infection, dermatitis, obesity, diabetes mellitus, abdominal pain, adjustment disorder, bronchitis, and trauma (118). This list suggests that the centers were not seeing a large number of people with dementia at that time. A current list, if one were available, might include other diagnoses. It is also possible that CHCs are providing primary health care for some people with dementia but not identifying their dementia. The 1986-87 La Jolla study mentioned earlier found that some CHCs lacked specific means to detect mental disorders, including dementia. The reason was that many of them used adult, rather than geriatric, screening criteria. The adult criteria miss dementia and other problems that are prevalent among the elderly (693).

As discussed later in this section, some CHCs provide case management for the clients of State-funded long-term care programs that serve elderly and disabled people, including people with dementia. In addition, at least one CHC, Eastern Shore Rural Health System, Inc., in Virginia, has a special Alzheimer's Disease Project that provides public education about Alzheimer's disease as well as caregiver support groups and respite services (see box 8-D).

Although the extent to which CHCs serve people with dementia is not known, it is reasonable to assume that CHCs that serve large numbers of elderly people are more likely than other CHCs to serve people with dementia. As noted earlier, in 1985, only 9 percent of Section 330 CHCs' clients were over age 65. The percentage of elderly clients varies greatly among CHCs. The 1986-87 La Jolla study found that depending on the CHC, elderly people made up from 2 to 46 percent of its client population (693). According to the National Association of Community Health Centers, the percentage of elderly CHC clients is generally lower in urban than in rural areas; in some large cities, elderly people make up only 5 percent of all CHC users (569).

The Health Resources and Services Administration (HRSA), which administers Section 330 grants at the Federal level, has initiated several efforts over the years to increase Section 330 CHCs' services for elderly people. In 1984, for example, it awarded $1.7 million in supplemental Federal funds to 57 Section 330 CHCs to pay for new or expanded programs for the elderly that might later be replicated by other CHCs (693).

HRSA has also sponsored joint initiatives with the Administration on Aging to increase collaboration among CHCs, State units on aging, AAAs, State and local health departments, and voluntary organizations that provide services for elderly people (420). In 1987, for example, HRSA and the Administration on Aging conducted regional workshops for personnel of State units on aging and associations representing CHCs at the State level (420,648). One intended outcome of the workshops was to help participating agencies overcome "turf" problems that often interfere with the coordination of services for elderly people.

As a result of the 1987 initiative, collaborative projects involving aging network agencies and CHCs were established in many States. In Kentucky, the State Community Health Center Association and the State Division on Aging developed a joint plan that included the goal of training case managers in the CHC and AAA systems to improve elderly people's access to both CHC and AAA resources (420). In Utah, four health education fact sheets—including a fact sheet on dementia—were developed for distribution to elderly people through CHCs, senior centers, and other elderly services agencies (420).

Some CHCs that have implemented successful programs to serve elderly people did this in collaboration with AAAs and other aging network agencies even before the 1987 initiative. The Shawnee Health Services and Development Corp., which operates three CHCs in southern Illinois that provide many services for elderly people, credits the success of its elderly services programs in part to coordination with the local AAA, senior centers, and other aging network agencies (631). Over the last 6 years, the number of elderly clients served by Shawnee's three CHCs has quadrupled, and the ratio of elderly clients to total CHC clients has tripled. The local AAA has paid for several programs implemented by Shawnee (648).

Linking Functions

Information and Referral

CHCs provide their clients with information about services and referrals to community service providers. OTA has no data on the types of referrals provided by CHCs, and these undoubtedly vary depending on a CHC's clientele and the training and experience of its staff. The purpose of CHCs is to furnish primary health care, however, and anecdotal evidence suggests that the referrals provided by CHCs are more often to other health care services than to the long-term care, social, or other services that also are needed for people with dementia.

OTA does not know how many CHCs maintain comprehensive lists of community resources that include the kinds of services that may be needed for people with dementia. Nor does OTA know how many, if any, CHCs serve caregivers at a distance.

Case Management

According to the National Association of Community Health Centers, CHCs pioneered and developed the concept of managed care (578). The focus of care management or case management in CHCs is generally on health care needs. If clients need hospital, nursing home, or acute home health care, or special medical services, CHC staff often arrange and monitor the provision of these services. In contrast, the findings of the few small studies that addressed the question of case management in CHCs suggest that CHCs generally do not provide the kind of comprehensive, ongoing case management that is needed by some dementia patients (478,693).

Most of the 10 CHCs in the 1986-87 La Jolla study did not provide their elderly clients with a comprehensive assessment that included social and environmental as well as health status (693). The professional staff of the 10 CHCs typically functioned individually and rarely came together as a team to develop a multidisciplinary plan of care for a client. Nor did they generally provide followup or ongoing monitoring of services other than health care services. Families frequently were not involved in a client's clinical evaluation, although they were involved in support groups, respite care, and home care programs in CHCs that provided these programs. A study of seven CHCs in New York found that "CHCs frequently lacked the social workers and/or community health aides necessary to make referrals and act as liaisons to the myriad of other agencies which may be involved with an elderly individual" (478).

Photo credit: Alzheimer's Association and Rush-Presbyterian/St. Luke's Medical Center.

The main function of community health centers is to provide primary health care. Consequently, the information and referrals and case management provided by community health centers generally focus on the health care needs of their clients.

The amount of contact a CHC has with other community organizations is relevant to its ability to perform case management. According to the National Association of Community Health Centers, most CHCs have contact with many different agencies—social service agencies, community action programs, local government offices, and other medical and dental providers—that allows for extensive referrals between CHCs and other agencies (569). A 1984 study of 32 communities showed that CHC coordination with other agencies was increasing (924), but the 1986-87 La Jolla study concluded that even some of the 10 CHCs that were identified by La Jolla as having good programs for elderly people had not established relationships with some of the types of agencies that are most likely to provide services for elderly people (693).

Box 8-D—The Alzheimer's Disease Project of Eastern Shore Rural Health System, a Community Health Center in Virginia

Eastern Shore Rural Health System (ESRHS) is a community health center that provides medical and other services at three clinic sites in two Virginia counties on the southern tip of the Delmarva Peninsula, which lies between the Chesapeake Bay and the Atlantic Ocean. ESRHS serves a rural area with a population of 50,000 people, half of whom have incomes below the Federal poverty level and half of whom are black. Since 1982, ESRHS has established a variety of programs for elderly people, often with encouragement and funding from the Eastern Shore Area Agency on Aging/Community Action Agency, which is the local AAA. From 1983 to 1986, the percentage of ESRHS's clients who were elderly increased from 13 to 18 percent.

ESRHS's Alzheimer's Disease Project was initiated in 1984, when the local AAA gave ESRHS a $1,000 grant to establish and run support groups for family caregivers of Alzheimer's patients. In 1985, the project was expanded to provide in-home respite services for Alzheimer's family caregivers with a $7,000 grant from the Dementia Center of Hampton Roads (Virginia). Currently, family caregivers of people with dementia can receive up to 20 hours of respite care a week. Since 1986, funding for such services has been provided via an annual grant from the Hampton Roads Alzheimer's Association Chapter, and fees to caregivers for respite services are based on a sliding scale. The Alzheimer's Disease Project generally provides respite services to about 10 families at a time. To assess how the patients and families who are receiving the respite services are managing, the project coordinator and a geriatric nurse practitioner make home visits every 4 to 6 weeks.

In addition to offering support groups and respite services for the caregivers, ESRHS's Alzheimer's Disease Project provides public education about dementia and about ESRHS's services for people with dementia and their families. Public education is provided through brochures, a quarterly newsletter, articles and advertisements in the media, and community meetings. The Alzheimer's Disease Project also provides training related to dementia and the care of dementia patients for the staff of local nursing homes and home health agencies and for other people who work with dementia patients and their families. Lastly, the Alzheimer's Disease Project furnishes families with home health care supplies, including wheel chairs; incontinence supplies; skin care products, such as alternating pressure pads; plate guards and special cups for feeding; and other assistive devices.

SOURCES: S. Ray, N. List, R. Clinkscale, et al., La Jolla Management Corp., Columbia, MD, "Assessment of the Current Utilization of C/MHCs by the Elderly and an Assessment of the Capability of C/MHCs To Develop Comprehensive Community-Based Primary Care Health Service Systems for the Elderly," prepared for the Bureau of Health Care Delivery and Assistance, Health Resources and Services Administration, Public Health Service, U.S. Department of Health and Human Services, Rockville, MD, July 1987; C.D. Rienerth, executive director, Eastern Shore Rural Health Services, Inc., Onancock, VA, personal communication, Aug. 1, 1989; G.V. Podelco, executive director, Eastern Shore Area Agency on Aging/Community Action Group, Onancock, VA, letter to the Office of Technology Assessment, U.S. Congress, Washington, DC, Aug. 16, 1989; and C. Dever, development director, Eastern Shore Rural Health Services, Inc., Onancock, VA, personal communications, Aug. 2, 1989, and Sept. 9, 1989, and quarterly reports on ESRHS's Alzheimer's Disease Project for June 14, 1984, Jan. 25, 1985, Oct. 25, 1985, Apr. 25, 1986, July 25, 1986, Oct. 24, 1986, Jan. 27, 1988, July 27, 1988, and for the period January to May 1989.

On the other hand, at least a few CHCs provide comprehensive, ongoing case management, often in connection with a State-funded long-term care program. Shawnee Health Services and Development Corp. in Illinois, described earlier in this section, has a contract with the State of Illinois to function as a "Care Coordination Unit" to provide case management for people who are eligible for Illinois' Community Care Program—i.e., people who are over age 60 and functionally impaired enough to be eligible for Medicaid-funded nursing home care (631,648,693).[12] The case managers for this program are based in Shawnee's CHCs. AltaMed Health Services Corp., a CHC in Los Angeles, also provides comprehensive case management for some of its clients through two programs (see box 8-E).

Public Education

As noted in box 8-D, the Eastern Shore Rural Health System's Alzheimer's Disease Project uses brochures; newsletters; articles and advertisements in the media; and community meetings to inform the public about dementia and services for people with dementia. The CHCs in the 1986-87 La Jolla study used presentations to other community agencies, neighborhood groups, and participants in church meal programs to inform the people about their services for elderly people (693). Presumably, other CHCs use similar methods. The focus of their public education efforts probably reflects their main interests, however, which often do not include caring for elderly people or people with dementia.

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[12] See ch. 7 for further information about Illinois' Community Care Program.

CHCs have the opportunity to provide patient and family education in conjunction with their health screening and primary health care services, and many do so. Once in the community to screen for high blood pressure or diabetes, for example, CHCs can furnish people with information about any of a variety of health problems and about services of the CHC and other community agencies that may be available to address the problems. OTA does not know how often CHCs use such opportunities to provide patient and family education about dementia and services for people with dementia.

Outreach

CHCs conduct outreach programs of various kinds, but no information is available about how successful they are in identifying people with dementia or people who live alone and otherwise might not seek care. A 1986 study of 10 CHCs conducted by the National Association of Community Health Centers found that all 10 centers studied provided services in many locations, including senior centers, adult day care and congregate meal sites, and other locations where the elderly frequently convene (569). Still, lack of outreach services beyond these locations was identified as a barrier to the use of CHCs' services by elderly people.

Role in Allocating Services and Funding

Some CHCs that provide case management under contract with State long-term care programs—e.g., AltaMed, described in box 8-E—also determine clients' eligibility for services paid for by the programs. In general, however, CHCs do not control people's access to services other than the CHCs' own services.

Summary

As agencies that might be designated to constitute a national system to link people with dementia to services, CHCs offer several advantages:

- CHCs exist at more than 2,000 sites across the country.
- CHCs reach low-income people and members of minority groups who often are not reached by other health care delivery systems.
- CHCs are located in many areas where other service agencies are absent, including rural and other medically underserved areas.
- CHC's usually provide medically focused case management for their clients.
- Many CHCs employ a full complement of health care professionals, including physicians, physicians' assistants, nurses, social workers, therapists, dentists, health educators, and others who might be able to provide multidisciplinary assessments and care plans for people with dementia.

Despite these advantages, most CHCs are not currently well equipped to link people with dementia to services for several reasons. CHCs' main purpose is to provide primary health care services. The type of case management performed by CHCs is typically medical in orientation, and most CHCs do not provide or routinely link people to the full range of long-term care, social, legal, financial, and other services that may be needed for people with dementia.

Many CHCs serve mostly mothers and children. Such CHCs are unlikely to have staff with training, expertise, or interest in working with people with dementia. Over the years, CHCs have tended to underserve elderly people. Moreover, even when CHCs do see elderly people, they often do not use screening criteria that can identify dementia in older people. In addition, many CHCs do not have relationships with the types of community agencies that are most likely to serve people with dementia.

As noted earlier, some CHCs have programs specifically for people with dementia, and some provide public education, information and referrals, outreach, and case management for elderly and disabled people, including people with dementia. The existence of these programs in some CHCs suggests that they could also be implemented in other CHCs. Implementing them without a large infusion of funds for new programs, however, would require a significant redirection of many CHCs' efforts, which would adversely affect other CHC programs and client populations.

Lastly, a national linking system composed of CHCs could be directly funded by the Federal Government through the approximately 600 CHCs

Box 8-E—The Linking Programs of AltaMed Health Services, a Community Health Center in Los Angeles, California

AltaMed Health Services Corp. operates a community health center (CHC) with several locations in an economically depressed, medically underserved area of East Los Angeles that has a predominantly Hispanic population. AltaMed began developing programs for elderly people in 1981, and subsequently became the first CHC in California to be licensed to provide adult day health care and the first Hispanic program to receive such licensure.

In addition to providing adult day health care, AltaMed currently operates two programs that link people to services:

- the Linkages Program, and
- the Multi-Purpose Senior Services Program (MSSP).

The Linkages Program is a program operated by AltaMed under contract with the State of California. The Linkages Program provides assistance in locating and arranging services for elderly and disabled people who are at risk of nursing home placement, but not necessarily impaired enough to be eligible for nursing home care paid for by Medi-Cal (California's Medicaid program). Some Linkages clients only need telephone referrals or help with arranging services on a one-time basis. Others need and receive short- or long-term case management. As of 1987, AltaMed's Linkages Program was serving about 200 clients, 70 percent of whom were over age 60. The Linkages Program does serve individuals with dementia, but OTA does not know how many.

MSSP is a Medicaid 2176 waiver program that AltaMed has operated under contract to the State of California since 1986. The program provides comprehensive, ongoing case management for elderly people who are eligible for nursing home care according to Medi-Cal requirements but choose to remain at home. MSSP's clients receive an initial in-home assessment, referrals and assistance in arranging and monitoring needed services, monthly followup either by phone or in person, and reassessment at 6-month intervals by a nurse/social worker team. MSSP also pays for in-home and other services for clients if other funding for the services is not available. AltaMed's MSSP program serves individuals with dementia, although OTA does not know how many.

SOURCE: S. Ray, N. List, R. Clinkscale, et al., La Jolla Management Corp., Columbia, MD, "Assessment of the Current Utilization of C/MHCs by the Elderly and an Assessment of the Capability of C/MHCs To Develop Comprehensive Community-Based Primary Care Health Service Systems For the Elderly," prepared for the Bureau of Health Care Delivery and Assistance, Health Resources and Services Administration, Public Health Service, U.S. Department of Health and Human Services, Rockville, MD, July 1987.

that currently receive Section 330 grant funds. To include in the linking system the other 500 to 750 CHCs that do not receive Section 330 grants would require the development of new criteria for identifying CHCs that would encompass these CHCs.

ALZHEIMER'S ASSOCIATION CHAPTERS

The Alzheimer's Association, also known as the Alzheimer's Disease and Related Disorders Association (ADRDA), is a national, privately funded, voluntary association of families, service providers, scientists, health care professionals, and other concerned individuals, founded in 1980 to confront the problems of Alzheimer's disease and related disorders. The association has five primary goals:

- to support research into the cause, treatment, cure, and prevention of Alzheimer's disease and related disorders;
- to stimulate awareness of Alzheimer's disease among the public and professionals;
- to encourage the formation of Alzheimer's Association chapters to create a nationwide support network for families of people with Alzheimer's disease;
- to advocate for Federal, State, and local public policies and legislation to assist Alzheimer's patients and their families; and
- to provide community programs and services for people with Alzheimer's disease and their families (16).

As of May 1990, the Alzheimer's Association had 210 chapters in 49 States (every State except Alaska) (461).

OTA has included Alzheimer's Associations chapters in its analysis of agencies that might constitute a national system to link people with dementia to services because the Alzheimer's Association specializes in educating the public about dementia and

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Box 8-F—The Wisconsin Alzheimer's Information and Training Center

In 1985, the Wisconsin legislature passed a bill to establish the Wisconsin Alzheimer's Information and Training Center. Following competitive bidding, the Southeastern Wisconsin Chapter of the Alzheimer's Association was chosen to develop and operate the center.

The goals of center are as follows:

- to disseminate information about Alzheimer's disease and related disorders through printed and audiovisual materials, training, technical assistance, and a telephone hot line;
- to increase service providers' knowledge about Alzheimer's disease and related disorders;
- to identify the needs of Wisconsin's Alzheimer's patients and their families; and
- to link families and other caregivers of Alzheimer's patients to appropriate services.

During 1984 and 1985, a statewide needs assessment was conducted to gather information about services in Wisconsin. This and other available information was computerized and has since been updated regularly for use in providing information and referrals and in advocating for new services.

The Wisconsin Alzheimer's Information and Training Center provides information free of charge to anyone who calls, including families, health care and social service professionals, community agencies, and voluntary organizations. Most requests for information are made through the center's toll-free 800 telephone line. Staff members and trained volunteers, most of whom are Alzheimer's family members, respond to the calls. Callers are given information about State-funded respite care and other community services and up-to-date information on Alzheimer's disease, caregiving, and legal issues. Some family caregivers require telephone counseling, and their calls often last between 30 to 45 minutes.

Out-of-State callers who are seeking services for a relative with Alzheimer's disease living in Wisconsin are generally referred to local service providers. Wisconsin residents seeking services for a relative with Alzheimer's living in another State are referred to an Alzheimer's Association chapter in that State.

The center maintains a lending library of Alzheimer's books, videos, slides, pamphlets, and brochures, and publishes original pamphlets, brochures, slides, and audio/video cassettes with Alzheimer's information. The center provides caregiver training and offers physicians and other health care professionals a program to familiarize them with available specialized Alzheimer's medical services and care facilities. The center also offers technical assistance to county agencies, service providers, and other organizations that are providing or are interested in developing services, such as support groups, adult day care, in-home respite care, specialized residential care, and assessment units for Alzheimer's patients. In 1989, the center sponsored its third annual statewide conference on Alzheimer's disease that involved family members, professionals, paraprofessionals, and volunteers. It has conducted over 100 workshops throughout the State on various facets of Alzheimer's disease.

The day-to-day activities of the center are managed by its paid staff (including a social worker, a nurse, and 2 recreation therapists) and about 12 volunteers. The center has an advisory council of 18 people who are family caregivers or representatives of community organizations such as the American Association of Retired Persons, county agencies on aging, nursing homes, adult day centers, and home care agencies. Other Wisconsin Alzheimer's Association chapters participate in an advisory capacity.

SOURCE: B. Keyes, "Wisconsin Alzheimer's Information and Training Center," program description, Milwaukee, WI, December 1987.

in providing information and referrals for people with dementia and their families. The association's national office develops and distributes many different types of public education programs and materials about dementia. The national office also has a toll-free 800 telephone line to give callers information about Alzheimer's disease and to refer them to local chapters for help. Alzheimer's Association chapters distribute the public education materials developed by the national office, and many chapters also develop and distribute their own public education materials. In addition, chapters sponsor meetings, conferences, and other events to educate the public about dementia. Lastly, Alzheimer's Association chapters are required by the national association to have a newsletter and a telephone information and referral service, usually referred to as a "helpline" (461).

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Overview of the Agencies

The Alzheimer's Association's national headquarters is in Chicago, Illinois. In addition to developing and distributing public education programs and materials and operating the toll-free 800 telephone line, the national office raises and allocates funds for biomedical research on Alzheimer's disease and, to a lesser extent, for research on the care of people with Alzheimer's disease and related disorders.[13] The national office coordinates the activities of the association's national board and the chapters, provides technical consultation to service providers and other organizations, and coordinates the association's advocacy efforts at the Federal level. In 1987, the association's national office had a paid staff of 100 people and a budget of $11 million funded with contributions from individuals, foundations, and corporations (313, 325).

The Alzheimer's Association's 200 chapters are diverse, ranging from large chapters run by both paid staff and volunteers to small chapters run entirely by volunteers. Each chapter is a separate corporation and generates its own funds through private contributions. The amount and kinds of services a chapter can afford to offer depend largely on the funds it can generate locally (484). The association's national office estimated that in 1988 the annual budgets of individual chapters ranged from $10,000 to $500,000, depending on chapter size and fundraising ability (484).

Most chapters use only private funds to finance their programs, but some chapters receive public funds for various programs. One example is the Southeastern Wisconsin Chapter, which was selected by the State of Wisconsin in 1985 to operate the Wisconsin Alzheimer's Information and Training Center. The center's public education, information and referral, and other programs are described in box 8-F. Funds for the center are provided by the State. The operating cost is $150,000 a year (410).

In addition to the chapters' public education and information and referral programs, which are discussed at greater length later in this section, the chapters provide many other types of programs and services. Many chapters provide training about dementia and caregiving techniques for family caregivers, service providers, and others. In addition, all Alzheimer's Association chapters offer caregiver support groups. As of 1988, chapters throughout the United States were sponsoring a total of 1,500 caregiver support groups, all of which were free and open to the public (313). These groups provide their attendees with peer support, informal counseling, and information about local service providers.[14] Some chapters also provide short-term counseling for some family caregivers.

As of 1988, about 70 Alzheimer's Association chapters were providing some form of respite services for Alzheimer's patients and their caregivers (313, 325). Some chapters use trained volunteers to provide respite care; some use paid respite providers; and some use both. When paid respite providers are used, chapters typically charge a fee based on the family's ability to pay and subsidize the remaining cost of the services from chapter resources. A few chapters have a training program for respite workers and maintain a list of trained respite workers to whom they can refer families and others (183).

Advocacy on behalf of Alzheimer's victims and their families is one of the key functions of the Alzheimer's Association and its chapters. At the national level, the Alzheimer's Association testifies at congressional hearings and advocates for public policies to meet the unique needs of people with dementia and their caregivers. The association also joins coalitions of national groups to support legislation and regulatory measures of importance to people with dementia and their families. Alzheimer's Association chapters conduct public awareness campaigns to draw public and legislative attention to the problems of Alzheimer's disease. Many of the chapters advocate with State and local government officials and legislators for programs to benefit people with dementia and their families. The association develops materials, conducts workshops, and sponsors public policy forums to help chapter members become more effective advocates. As a result of all these activities, it is probably correct to say that over the past 10 years, the Alzheimer's Association has been the driving force responsible

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[13] In addition to its sponsorship of research, the Alzheimer's Association has sponsored several demonstration projects and is currently co-sponsoring with the Robert Wood Johnson Foundation a demonstration project in which 19 adult day centers have received funding to create comprehensive systems of care for people with dementia (712). The project is described in the last section of this chapter.

[14] The role of caregiver support groups in providing their attendees with information about the quality of available services is discussed in ch. 5.

ALZHEIMER'S

Photo credit: Alzheimer's Association

The Alzheimer's Association has been an effective advocate for increased Federal funding for biomedical research and improved services for people with dementia.

for a 10-fold increase in Federal spending for biomedical research on Alzheimer's disease in that period and for many of the other changes in Federal, State, and local laws and regulations that affect the availability of appropriate services for people with dementia.

The Alzheimer's Association has grown rapidly since its establishment in 1980. New chapters are constantly being formed, and the functions of the national office and the chapters are expanding. As this growth has occurred, the number of paid staff in the national office and the number of chapters that have paid staff has increased. Although some chapters still operate without any paid staff, it is clear that the association is becoming less an organization operated by volunteers and more an organization directed by volunteers but operated on a day-to-day basis by paid staff and volunteers.

To learn about the capacity of Alzheimer's Association chapters to function as the basis of a national system to link people with dementia and their caregivers to services, OTA contracted for a survey of Alzheimer's Association chapters (484).[15] A questionnaire was developed and mailed to 10 chapters. The chapters were selected to reflect diversity in size, in services provided, in composition of staff (i.e., volunteer or paid), in type of area served (i.e., urban, suburban, or rural), and in other characteristics. The 10 chapters surveyed by OTA's contractor were:

- the Palm Beach County Chapter,
- the Detroit Area Chapter,
- the New York City Chapter,
- the Honolulu Chapter,
- the Albuquerque Chapter,
- the Central Virginia-Lynchburg Chapter,
- the Eastern Massachusetts Chapter,
- the Western North Carolina Chapter,
- the North Central Montana Chapter, and
- the Greater Kansas City Chapter (484).

OTA's contractor interviewed each chapter's president or executive director by telephone to obtain answers to the questions. Some of the survey findings are presented in the following discussion.

For several reasons, caution must be used in generalizing from the results of the survey. The number of chapters surveyed was small, and the individual chapters surveyed were not randomly selected. Moreover, the survey was conducted in early 1988, and, as noted above, many Alzheimer's Association chapters have expanded their programs and services since then (461). Nevertheless, the main conclusion of the survey—that Alzheimer's Association chapters vary greatly in the extent and sophistication of their programs to link people with dementia to services—is undoubtedly still true in 1990.

Who Is Served

Family members are the primary users of Alzheimer's Association chapters' services, but friends and neighbors of people with Alzheimer's disease, health care and social service professionals, other service providers, staff of State and local government agencies, researchers, journalists, students, and some people who have Alzheimer's disease also contact the chapters for various reasons (186,484). Family members are the primary users of the chapters' telephone helplines and support groups and the sole users of chapters' short-term counseling and respite services.

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[15] A complete report on the survey of chapters conducted for OTA is available from the National Technical Information Service in Springfield, VA (see app. A).

Alzheimer's Association chapters respond to requests for information and assistance from anyone who calls, but particularly from family members of people with dementia. Certain types of family caregivers—notably ethnic minority caregivers, poor caregivers, and caregivers who live in remote areas—have been less likely than other types of family caregivers to seek help from Alzheimer's Association chapters. The 10 Alzheimer's Association chapters surveyed for OTA in 1988 reported that few ethnic minority individuals were participating in their programs (484). Nine of the 10 chapters reported that they were not reaching particular groups, including blacks, Hispanics, Native Americans, and Asian Americans.

Currently, the Alzheimer's Association's national office and some chapters are expanding their efforts to reach ethnic minority caregivers of people with dementia (183,461). The national office has made available to chapters training and support materials to encourage minority participation and set apart a half-day of the association's annual meeting, held in October 1989, to discuss minority issues (461). Some chapters have established support groups specifically intended for ethnic minority caregivers (461,484).

Some of the 10 chapters surveyed for OTA in 1988 reported that they were not reaching low-income dementia patients and their caregivers or patients and caregivers who live in remote areas (484). Three of the 10 chapters reported problems in reaching low-income people. Interestingly, three chapters said they were not reaching people with high incomes. Five of the 10 chapters reported problems in reaching people with dementia and their caregivers who live in rural areas; one chapter indicated that it has a toll-free telephone line to be more accessible to these caregivers.

Only one of the 10 surveyed chapters specified a problem in reaching people with dementia who live alone and have no family members or other informal caregiver to help them. Anecdotal evidence indicates, however, that Alzheimer's Association chapters generally focus on serving family caregivers of people with dementia and may not expect to serve many individuals with dementia who live alone and have no caregiver (183,461,485). The available data on who is served by chapters indicate that chapters serve very few such individuals (186,484).

Linking Functions

Information and Referrals

As noted earlier, each Alzheimer's Association chapter is required by the national association to have a telephone "helpline" to provide callers with information about Alzheimer's disease and to refer them to local service providers (461). The number of calls handled by chapter helplines and the sophistication of their information and referral procedures vary greatly from one chapter to another. Larger chapters with paid staff generally handle larger numbers of calls. The Cleveland Chapter's helpline (see box 8-G) received more than 3,200 calls in the 4-month period from April through July 1988 (186). Over the past 3 years, the Detroit Area Chapter's helpline received 2,000 to 3,000 calls a year (484). In contrast, some small chapters offering strictly "volunteers serving neighbors" programs report as few as 3 to 4 calls a week (484).

Most calls received by chapter helplines are from family caregivers. As noted in box 8-G, 80 percent of the documented calls received by the Cleveland Chapter's helpline were from family caregivers (186). In 1988, the New York City Chapter reported that 70 percent of the 35 to 50 calls received daily by its helpline were from family caregivers living in the area; the other 30 percent were from out-of-State families seeking help for a relative living locally, friends, neighbors, sitters, individual service providers, agencies, clergy, students, nursing homes, lawyers, a few physicians, and people who feared that they might have Alzheimer's disease (484).

All 10 of the Alzheimer's Association chapters surveyed for OTA in 1988 reported using trained volunteers to respond to helpline inquiries (484). Many of these helpline volunteers were family caregivers of people with Alzheimer's disease. Seven of the 10 chapters surveyed for OTA in 1988 had a paid professional on staff, usually a social worker or nurse, who trained and supervised the helpline volunteers, served as a helpline consultant, and answered some helpline calls.

People call chapter helplines for various reasons and receive many different kinds of responses. Box 8-G discusses the reasons given by callers to the Cleveland Chapter's helpline. Table 8-1 lists the needs expressed by people who called the Detroit

Box 8-G—The Cleveland Alzheimer's Association Chapter's Helpline

The Cleveland Chapter of the Alzheimer's Association has a telephone helpline operated by both volunteers and paid staff. In a typical month, the helpline receives more than 800 calls. If a caller requests copies of printed materials or referrals to services, a form is completed to document the call. In the 4-month period from April through July 1988, the helpline received 3,251 calls, 446 of which (about 1 out of 7) resulted in the completion of a helpline form.

Sixty percent of the 446 documented helpline calls received in that period were either requests for general information about Alzheimer's disease or requests to be placed on the chapter's mailing list; 25 percent were requests for specific information from the chapter's bibliography or about particular services. Eighty percent of the 446 calls were from family members of a person with dementia, and 13 percent were from professionals requesting information for their clients. Ten calls during the 4 months were from students working on class projects; 4 were from people interested in volunteer opportunities; and 6 were from individuals who were worried about their own memory loss. Twelve calls were from local people concerned about a person with Alzheimer's disease who lived outside of the Cleveland area, and 7 calls were from people out-of-town who were concerned about someone living locally.

From April 1988 through July 1988, the helpline referred 40 callers to specific service providers. As part of a study conducted for OTA in 1988 (see app. A), 26 of these 40 callers were subsequently interviewed. All 26 were caregivers of a person with dementia. When asked why they had called the helpline, 20 of the 26 caregivers said they had called to get the names of people or organizations offering services for people with dementia; 13 said they had wanted help deciding what types of services would be best for the person; 8 said they had wanted to know what kinds of tasks an agency or professional caregiver could be expected to do; 8 said they had called to find out the usual cost of hiring someone to provide in-home services; 6 said they had sought information about what types of services are paid for by Medicare or Medicaid; and 4 said they had called to discuss a problem the patient or the caregiver had with a service provider.

Some of the 26 caregivers said they had called for general information in order to understand a demented person's behavior and to figure out what to expect and how to respond. A women concerned about her sister's forgetfulness explained, "I wanted to know what could be done if she had Alzheimer's disease." A daughter who stayed with her 80-year old mother on weekends noted: "I wanted to find out if mom could stay alone; I didn't know when I called that it was dementia or what dementia was." A few caregivers said they had called the helpline just because they needed someone to talk to. As one spouse put it, "I quit work, and now that I'm home all day, I'm always thinking about our problem. I get lonely sometimes. Brothers and sisters are out of the country, and our son doesn't want to be bothered. You know—I had to talk about it."

When asked why they had called the helpline instead of another source of information, several of the 26 caregivers indicated that the Alzheimer's Association seemed the most appropriate place to call considering what they were dealing with. The wife of a 76-year-old man with dementia noted, "You know, people talk—you hear about things. Sounded like my husband, so I thought I could talk to someone there." Many of the caregivers reported reading an article or hearing something on television that gave them the idea to call the helpline. A nurse helping a friend obtain services for her spouse observed that "since they are specific in dealing with Alzheimer's disease, they would have the most information and resources." Three caregivers were referred to the helpline by a professional. Nine caregivers had contacted other community agencies before calling the helpline.

When asked whether they had found any aspect of the helpline particularly helpful, some of the 26 caregivers noted the caring attitude and attempts to facilitate service use on the part of the helpline's staff. Individual professionals were described as "very helpful," "very nice," and "gentle." Some caregivers particularly appreciated the thoroughness, promptness, or evidence of extra effort by the staff. One woman who called the helpline in desperation after calls to other agencies and hospitals explained, "I'm very pleased with the help I received from the Alzheimer's Association and the social worker. The social worker agreed to come to Dad's home to talk about Mother's problem."

SOURCE: S.K. Eckert, and K. Smyth, "A Case Study of Methods of Locating and Arranging Health and Long-Term Care for Persons With Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, May 1988.

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Table 8-1—Expressed Needs of People Who Called the Detroit Alzheimer's Association Chapter's Helpline and Responses Given by the Helpline, 1987

What did Helpline callers say they needed?	Percent of callers who expressed this need
General information	36 %
Referral for adult day care or respite care	23
Referral for medical care	11
Referral for nursing home	9
Help with patient management	5
Tributes	2
Referral for legal information or services	2
Referral to adult foster care	1
Autopsy	0.6
Financial information	0.4
Request for a speaker	0.3

Helpline responses	Percent of callers who received this response
Sent information	31 %
Referred to in-home respite	13
Referred to medical care	11
Referred to a support group	11
Referred to adult day care	9
Referred to nursing home	8
Telephone counseling	5
Onsite counseling	4
Arranged a speaker	0.3

SOURCE: N.L. Mace, "The Role of ADRDA Chapters in Providing Information and Referral Services for Persons With Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, 1988.

Alzheimer's Association chapter's helpline in 1987 and the responses given by the helpline. These figures are typical of the estimates given by the other chapters surveyed for OTA in 1988 (484).

Despite differences in the helplines operated by different Alzheimer's Association chapters, helplines have in common that they are informal and ask few questions before responding to inquiries; thus they pose minimal barriers to family caregivers in obtaining information and referrals (484). Responses to helpline inquiries are immediate and personal. The 10 chapters surveyed for OTA in 1988 consistently reported using an empathetic approach to callers: "We listen, and the caregivers tell us what they need" (484). Because many of the helpline volunteers have been caregivers themselves, and because the volunteers and paid staff members spend so much time talking to callers, families feel understood and supported. In the view of OTA's contractor, this listening/supporting function may be as valuable to families as the information and referrals they receive.

The information about available services that Alzheimer's Association chapters use to provide information and referrals comes from various sources. Some chapters, including the Greater Washington, DC Chapter, have compiled directories of community services that may be needed for Alzheimer's patients and their caregivers (267). For the most part, however, the methods used by chapters to obtain information about community services are less thorough. Some chapters use directories produced by other agencies. Many obtain information about community services through word-of-mouth reports from families or professionals on the chapters' board or through informal networking with other community agencies (484). Some chapters refer callers to other agencies for information about services (e.g., AAAs and family service agencies).

Two of the 10 chapters surveyed for OTA in 1988 were using computers to maintain information about community resources (484). The other eight chapters were using files, but three of them had plans to computerize their resource lists. One of the chapters was not using a computer to maintain its list of community resources because the chapter's volunteers were not comfortable with using a computer (484).

As noted in boxes 8-F and 8-G, at least some Alzheimer's Association chapters provide information and referrals for long-distance caregivers. The Cleveland Chapter, for example, serves both local families requesting information for a relative with dementia living outside the chapter's service area and families calling from out of town about a relative with dementia living in the Cleveland area (186).

Clearly, the capacity of Alzheimer's Association chapters to meet the information and referral needs of people with dementia and their families varies from one chapter to another. Some chapters have well-developed information and referral procedures and systematic methods for obtaining information about available services. Other chapters are still in the process of developing their information and referral helplines and do not have systematic methods of collecting information about available services (484). Anecdotal evidence and the findings of the survey conducted for OTA in 1988 indicate that most chapters do not have formal followup procedures to determine whether helpline callers for whom they provide referrals are successfully linked to the services they need, although some chapters do

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Box 8-H—The Alzheimer's Family Consultants Program of the Palm Beach County, Florida Alzheimer's Association Chapter

The Palm Beach County Chapter of the Alzheimer's Association offers care management for people with dementia through its Alzheimer's Family Consultants Program. From October 1988 to June 1989, the program provided care management for 361 people with dementia and 392 caregivers.

The Alzheimer's Family Consultants program provides care management free of charge, according to need, regardless of age or income. Most of the program's clients are Alzheimer's patients who live with a caregiver, but the program also serves patients who live alone. The local sheriff, police department, and community businesses refer people with dementia who live alone to the program.

The program has three full-time paid staff members: two registered nurses who serve as Alzheimer's family consultants, and a nurse supervisor. The program has received grants from two local government agencies: $11,000 from the City of Boca Raton in 1987, and $48,000 from the Palm Beach County Commissioners in 1988.

When a person with dementia enters the program, an Alzheimer's family consultant makes sure the person has had a thorough diagnostic evaluation, meets with the patient and family to discuss various care options, and then arranges services for them. The family consultant discusses with the family the patient's potential eligibility for Medicare, Medicaid and other sources of funding for services and makes certain the family gets an attorney's advice about legal and financial issues related to the care of the person with dementia.

The Alzheimer's family consultants frequently arrange for clients to attend a specialized Alzheimer's adult day program sponsored by the Palm Beach County Chapter. They may also arrange in-home respite care. If the family wishes, the family consultant will schedule the respite visits and negotiate prices with the respite care agency.

The Alzheimer's family consultants follow-up regularly with phone calls or home visits to be sure their clients are satisfied with the services they are receiving. The family consultants work with their clients throughout the course of the dementia or until the person with dementia enters a nursing home.

The Alzheimer's family consultants offer caregiving training to families and refer families to local support groups. They also educate other community organizations about Alzheimer's disease and provide technical assistance to service providers who are developing programs for people with dementia. In 1989, Alzheimer's family consultants provided training for Palm Beach police officers about how to recognize and manage people with dementia and participated in a program sponsored by the Palm Beach County Chapter to make available locator identification bracelets to help the sheriff's office identify lost and confused people and return them to their homes.

As the Family Consultants Program has become better known in the county, it has received an increasing number of requests from the community for help in crises involving people with dementia. The requests include calls from neighbors of people with dementia who believe the people are at immediate risk and calls from the police and other local officials who have identified a person with dementia who has no one to help him or her. Recently, the Family Consultants program has been asked to provide expert testimony in several guardianship cases involving individuals with dementia.

SOURCE: M.M. Barnes, executive director, Alzheimer's Association Palm Beach Chapter, Palm Beach, FL, personal communication, Sept. 8, 1989.

have such procedures. Several years ago, the association's national office put together a Helpline manual to assist chapters in developing their helplines.

Case Management

Few Alzheimer's Association chapters report that they provide case management, but many chapters perform certain case management functions, including helping caregivers define the kind of services they need and contacting service providers for some caregivers who are unable to do so themselves (461,484). OTA is aware of several Alzheimer's Association chapters that provide all five functions that OTA has defined as core case management functions, although the chapters may not call what they provide "case management." One example is the Palm Beach County Chapter, which provides what it calls "care management" through its Family Consultants Program (see box 8-H). It should be noted that the Palm Beach County Chapter's care management program serves people with dementia who live alone and have no informal caregiver to help them (54).

There is some discussion, at present, among Alzheimer's Association members about whether providing case management is a priority function for chapters. The discussion often flounders, however, on different definitions of what case management is. Some association members believe that providing case management (as they define it) is an essential part of the chapters' role in helping people with dementia and their families. Other members believe that chapters should concentrate their efforts on public education, information and referral, and other functions, such as training caregivers and providing respite services. Anecdotal evidence suggests, in the meantime, that the number of chapters that provide case management is increasing.

Public Education

As noted earlier, the Alzheimer's Association has an extensive public education program. The association's national office sponsors public service announcements and publishes and distributes books, articles, and brochures about all aspects of Alzheimer's disease and the care of people with dementia. These publications are available from the national office and from the chapters. The national office publishes a newsletter that is received by a half million people nationwide (473) and develops and circulates audiovisual materials to educate the public about Alzheimer's disease. Through its toll-free 800 telephone line, the national office answers questions from anyone about any aspect of the disease.

Alzheimer's Association chapters also develop and distribute many kinds of publications and audiovisual materials about Alzheimer's disease and the care of people with dementia. Some chapters have lending libraries with printed and audiovisual materials on these topics (473,484). Some chapters sponsor programs and public service announcements on radio and television. The chapters also participate in health fairs, community meetings, and conferences that provide opportunities to educate the public about Alzheimer's disease. As mentioned earlier, all chapters are required by the association to publish a newsletter, and the chapter newsletters are a source of information about Alzheimer's disease and the care of people with dementia for all who read them (461).

The national office supports the chapters' public education efforts in various ways, including the provision of up-to-date information about Alzheimer's disease and related issues. One objective of the national office is to encourage consistency among chapters in the information they provide for the public, particularly information about new scientific findings and potential treatments for Alzheimer's disease (461).

Outreach

Some Alzheimer's Association chapters have developed certain procedures to identify people with dementia who need assistance but are unlikely to contact a chapter or to seek help on their own. These procedures generally involve training individuals, such as police and bank employees, to identify people with dementia who may need assistance and to notify the chapter or someone else who can help. Alzheimer's Association chapters also approach physicians who may be treating people with dementia and encourage them to refer these people to the chapter for help. The 10 Alzheimer's Association chapters surveyed for OTA in 1988 said they rely on their public education programs and materials, including newsletters, other publications, and public service advertising, to reach people who may need their services. Of the 10 surveyed chapters, 6 reported that other agencies referred clients to them; 4 said they were listed in the yellow pages; and 4 said they were listed in handbooks published by other agencies. For the most part, the chapters said that they were successful in reaching white, middle-class families (484).

Role in Allocating Services and Funding

Alzheimer's Association chapters do not control access to or funding for services other than those they provide.

Summary

As agencies that might be designated to constitute a national system to link people with dementia to services, Alzheimer's Association chapters have many advantages:

- The Alzheimer's Association and its chapters provide many public education programs and materials about Alzheimer's disease, dementia, and the care of people with dementia.

- Alzheimer's Association chapters provide information and referrals for people with dementia and their caregivers.
- The public education, information and referral, and other programs and services provided by the Alzheimer's Association and its chapters are intended specifically to meet the needs of people with dementia and their caregivers.
- Alzheimer's Association chapters respond to inquiries from families and other informal caregivers in a flexible, personal, and nonbureaucratic way. Because of this and because of their focus on Alzheimer's disease and related disorders, families of people with dementia often experience a sense of being understood and supported.
- Some Alzheimer's Association chapters provide case management.

Despite these advantages, there would be certain drawbacks to designating Alzheimer's Association chapters as the basis of a national system to link people with dementia to services. First, the capacity of individual chapters to meet the information and referral needs of people with dementia and their caregivers varies. Some chapters have systematic procedures for developing and maintaining an accurate list of available services and sufficient paid staff and/or volunteers to operate an information and referral program that would meet the needs of all people with dementia and their caregivers in the chapters' service areas. Other chapters—particularly some of the small, volunteer-run chapters that rely on informal methods of gathering and dispensing information about services—might have difficulty operating a program that would meet those needs.

Another drawback to designating Alzheimer's Association chapters as the basis for a national system to link people with dementia to services is that many chapters do not have outreach procedures to identify people with dementia who live alone and have no informal caregiver to help them or people with dementia whose informal caregiver is unable for any reason to seek services for the person. In addition, although many chapters assist some caregivers in defining their service needs and contacting service providers, most chapters do not provide the comprehensive case management that would be necessary to locate, arrange, and monitor services for individuals with dementia who do not have an informal caregiver or for those that have a caregiver who is unable to follow through on arranging and monitoring services.

As discussed earlier, low-income and ethnic minority caregivers have been less likely than other caregivers to seek help from Alzheimer's Association chapters. The Alzheimer's Association's national office and some chapters have recently initiated special efforts to reach ethnic minority patients and caregivers. Such efforts require a substantial investment of chapters' limited resources, however, and it is unclear how many chapters will be able to commit the necessary resources.

With additional funds, many of the drawbacks cited above could be overcome. On the other hand, some existing Alzheimer's Association chapters might not want to change their current operating procedures to provide outreach and case management for all people with dementia, even if additional funds were available.

In considering the drawbacks to designating Alzheimer's Association chapters to constitute a national system to link people with dementia to services, it is important to note that some caregivers of individuals with dementia may be unlikely to contact an Alzheimer's Association chapter for assistance because they do not identify the individual's problem as Alzheimer's disease. This is probably especially likely to occur if the individual has serious physical impairments in addition to his or her dementia and has not been diagnosed as having Alzheimer's disease; it might also occur in some instances in which the individual has Parkinson's or Huntington's disease or any dementing disease or condition other than Alzheimer's disease. Additionally, anecdotal evidence indicates that some caregivers perceive a stigma associated with the diagnosis of Alzheimer's disease; they might not want to contact an Alzheimer's Association chapter for assistance. OTA does not know how many caregivers would be unlikely to contact an Alzheimer's Association chapter for any of these reasons. Certainly, as public awareness of Alzheimer's disease increases, any stigma associated with the diagnosis is likely to be reduced, and caregivers are more likely to identify the condition, even in an individual with serious physical impairments.

Finally, it is clear that if Congress designated a category of agencies other than Alzheimer's Association chapters to constitute the national linking system, the association and its chapters should be involved in planning the system, training the staff of the agencies that constitute the system, and monitoring its performance on an ongoing basis. Several examples of linking programs and systems in which Alzheimer's Association chapters function in this way have been described in this report (see, e.g., the description of Missouri's Alzheimer's helpline in box 7-A in ch. 7). As discussed in chapter 1, it is essential to involve the Alzheimer's Association and its chapters in planning the linking system and monitoring its performance in order to assure that the system is *dementia-friendly* and *dementia-capable*.

FAMILY SURVIVAL PROJECT

The Family Survival Project (FSP) has evolved from a task force of concerned families and community leaders who organized in the San Francisco Bay area in 1976 to assist caregivers of adults with progressive or irreversible brain impairment (199). Its first efforts included documenting the problems of caring for adults with irreversible brain impairment and advocating State and Federal laws to develop services for brain-impaired adults and their caregivers. In 1979, FSP received funding from the State of California to develop a community program of supportive services and training for the caregivers of brain-impaired adults. In 1984, the State of California decided to use FSP as the model for a statewide system. Since then, FSP has functioned in two capacities:

- As California's Statewide Resources Consultant, FSP helped establish a statewide network of 11 regional resource centers for families and caregivers of brain-impaired adults (3 in 1986, 3 in 1987, and 4 in 1988) and currently helps coordinate the network and performs a number of other statewide functions.[16]
- As the Bay Area Regional Resource Center, FSP serves as a regional resource center for the families and caregivers of brain-impaired adults in a 6-county area with about 5 million people (405).

FSP's clients include the families and caregivers of individuals with dementia, stroke, traumatic brain injury, brain tumor, and other diseases and conditions that cause brain impairment. The majority of its clients are caregivers of people with Alzheimer's disease and other diseases that cause dementia (200,235).

OTA has included FSP in its analysis of agencies that might constitute a national system to link people with dementia to services because FSP's functions as California's Statewide Resources Consultant and as the Bay Area Regional Resource Center closely parallel those OTA considers essential to an effective system for linking people with dementia to services. In addition, FSP's program has been duplicated throughout the State of California and might be duplicated elsewhere.

Overview of the Agency

In its capacity as California's Statewide Resources Consultant, FSP currently performs a number of functions:

- It operates a statewide information clearinghouse on topics related to brain impairment and the needs of caregivers.
- It publishes regular information letters and bulletins about regulatory changes, new programs, model programs, and research related to brain disorders and services for brain-impaired adults and their caregivers.
- It provides technical training and consultation to government agencies, service providers, and volunteer organizations interested in developing new programs for brain-impaired adults and their caregivers.
- It coordinates the activities of government agencies, service providers, and community organizations to develop programs and services for brain-impaired adults and their caregivers.
- It offers personnel at California's regional resource centers an initial orientation, inservice training sessions, and annual staff development conferences.
- It encourages public and private participation in the financing and provision of services for brain-impaired adults and their caregivers.
- It conducts social policy research on the extent and consequences of brain impairment for individuals and their families.
- It advocates public policy reforms to encourage the development of services for brain-impaired adults and their caregivers (102).

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[16] For information about California's statewide network of regional resource centers, see the discussion of California's linking programs in ch. 7.

As the Bay Area Regional Resource Center, FSP performs several additional functions:

- It provides information and referrals to programs and services to meet the needs of family caregivers of brain-impaired adults living in its service area.
- It conducts 3 support groups for caregivers of brain-impaired adults and regularly refers caregivers to over 100 other support groups in the region.
- It evaluates family caregivers' needs for supportive services and provides some supportive services directly (e.g., short-term counseling, family consultation, long-term care planning, and training on caregiving techniques) and other services via providers operating under contract (e.g., respite, transportation, legal and financial consultations, and neuropsychological evaluations) (199).

FSP derives the bulk of its funding from contracts with California's Department of Mental Health (200). For fiscal year 1987-88, FSP received $1,047,619, including $440,664 to function as the Statewide Resources Consultant, and $606,955 to function as the Bay Area Regional Resource Center; each of the 10 other regional resource centers received about $200,000. For fiscal year 1989, the California legislature appropriated $5.2 million for both FSP and the 10 other regional resource centers (14). FSP also receives funds from foundation grants, private donations, and fees or donations for services from caregivers.

FSP's staff serves both the Bay Area Regional Resource Center and the Statewide Resources Consultant (199). All of these individuals are knowledgeable about dementia, and most hold bachelor's and/or master's degrees in human services or social work. Some of FSP's staff serve as "resource persons" for the Statewide Resources Consultant. FSP's Research and Information Program's three staff members operate the statewide information clearinghouse and conduct social policy research related to brain impairment (200). FSP's Education and Service Program's three staff people educate the public about brain impairment and offer technical assistance to professionals and organizations interested in developing programs and services for brain-impaired adults and their caregivers (405).

FSP's Bay Area Regional Resource Center staff members include two intake and resource specialists, who respond to initial inquiries and maintain regional resource files; a family consultant, who counsels caregivers about legal concerns, appropriate respite care, and other issues related to caregiving; two social workers, who perform indepth assessments of individual families' needs, develop plans of care, provide short-term counseling, arrange for respite and other services made available by providers under contract to FSP, and make home visits if and when respite services are initiated; and a regional training specialist, who offers family training on patient management and organizes family support groups (405).

Public advocacy in support of programs and services for brain-impaired adults and their caregivers has been a primary function of FSP since its inception (199). In 1979 and 1983, FSP advocated California legislation that led to the establishment of the Statewide Resources Consultant and the statewide system of regional resource centers. FSP currently organizes conferences and prepares testimony and reports for use in developing services for brain-impaired adults and their caregivers throughout California. FSP also distributes information to over 1,200 "key contacts" that it uses to coordinate advocacy activities and promote cooperation among local, State, and national organizations.

Who Is Served

FSP's primary focus is on serving the families and other caregivers of brain-impaired adults, including individuals with dementia. Anyone who calls, visits, or writes FSP, however, can receive information about brain impairment and related programs and services. In 1987, the Statewide Resources Consultant responded to about 700 initial inquiries from callers in other States or in regions of California without an operating regional resource center (200). The Bay Area Regional Resource Center responded to about 1,500 initial requests for information and referrals from callers in the more immediate area: 1,001 from families and other informal caregivers of brain-impaired adults, 473 from service providers and members of the general public, and 2 from brain-impaired adults.

All the caregivers of brain-impaired adults who want to participate in training events and support groups offered by FSP at the Bay Area Regional

Resource Center are able to do so. In 1987, 1,287 people attended FSP-sponsored training events and 99 caregivers attended an FSP-sponsored support group (405). Caregivers of brain-impaired adults living in a six-county service area are eligible for counseling, respite care, and other supportive services provided by or through the Bay Area Regional Resource Center, but not all caregivers receive such services. In order to receive them, caregivers must first be referred by FSP's intake and resource specialist to the family consultant or social workers for an indepth needs assessment. In 1987, 636 of the 1,001 caregivers who contacted the Bay Area Regional Resource Center for the first time chose to go through the intake screening process, and 251 of them were referred for an indepth needs assessment. Of the 251 referred for assessment, 106 received respite care, 90 received consultation/planning, 39 received legal/financial consultation, 8 received counseling, and 8 received neuropsychological patient evaluations (405).

The majority (62 percent) of the 636 caregivers who chose to go through FSP's intake screening process in 1987 were taking care of an individual with dementia. The remaining caregivers were taking care of individuals with stroke (18 percent), traumatic brain injury (16 percent), a brain tumor (4 percent), and other diseases and conditions that cause brain impairment (4 percent) (200).

For consultation/planning, legal/financial consultations, counseling, and family support groups, FSP generally solicits a "suggested donation" from the brain-impaired adult's family. For respite care, FSP charges a copayment based on the family's income. In 1987, 75 percent of the 106 families who used FSP's respite services contributed to the cost of respite care; the average cost for FSP to provide a family with respite services for a month was $327, and on average, $27 of this was paid by the family, and $300 was paid for with State funds (200).

Linking Functions

Information and Referral

Providing information and referrals to the family caregivers of brain-impaired adults is a principal function of FSP, both as California's Statewide Resources Consultant and as the Bay Area Regional Resource Center. As noted earlier, in its capacity as the Statewide Resources Consultant, FSP maintains a statewide database of information about brain impairment, related caregiving problems, and services for brain-impaired adults and their caregivers. FSP collects data from regional resource centers on caregivers, patients, services, and costs of services in their regions for use in the statewide database, and it analyzes these data to identify unmet needs (200). FSP also refers callers to regional, State, and national programs and services for brain-impaired adults and their caregivers.

In its capacity as the Bay Area Regional Resource Center, FSP maintains comprehensive lists of formal and informal in-home and community services for brain-impaired adults and their caregivers in each county of its six-county service area. It also maintains a resource library that distributes information packets and lends books, videotapes, and reference materials about brain impairment and related issues. FSP can respond to requests for information made by telephone, in writing, or in person. It has a toll-free telephone number to serve long-distance caregivers seeking information and referrals to services for a brain-impaired relative living in the San Francisco Bay area.

The Bay Area Regional Resource Center's intake and resource specialists maintain regional resource files and take most calls from first-time callers. When someone calls FSP, these staff members listen and then try to assist the caller in determining what he or she needs so they can refer the caller to appropriate resources. Some callers are referred directly to other community agencies that provide specific services. Other callers are referred to FSP's family consultant or to social workers for followup assistance with legal concerns, respite care, and a variety of other issues related to caregiving. FSP's intake and resource specialists can handle as many as 30 calls a day.

First-time callers who do not wish to go through the intake screening process are sent packets of written material detailing FSP's programs and other community programs and services for brain-impaired adults and their caregivers. In 1987, the Bay Area Regional Resource Center sent about 900 packets of written materials to first-time callers. All of the packets include the telephone number of FSP's family consultant in case an inquirer wants more information or assistance (200).

Case Management

Although the organization does not say that it provides case management, FSP provides all five functions that are included in OTA's definition of case management for some of the people it serves as the Bay Area Regional Resource Center. If an intake and resource specialist at FSP believes that a family caregiver or other caller needs assistance beyond information and referral, he or she refers the caller for an indepth needs assessment (405). The assessment of the caregiver's and brain-impaired adult's needs is conducted either by FSP's family consultant or by one of FSP's social workers, who gathers information through an interview with the caregiver on the telephone, at FSP's office, or at the caregiver's home. The purpose of the assessment is four-fold:

1. to determine what functional problems of the brain-impaired adult necessitate additional services,
2. to determine how the caregiver perceives the caregiving situation,
3. to determine what impact caregiving has had on the caregiver's physical and/or mental health, and
4. to collect demographic data to assist in developing a statewide database on caregivers of brain-impaired adults.

After FSP's family consultant or social worker assesses the caregiver's and brain-impaired adult's needs and starts a case file, he or she recommends services. The recommended services are usually provided either directly by FSP (e.g., short-term counseling, family consultation, long-term care planning, and training on caregiving techniques) or by service providers under contract to FSP (e.g., respite, transportation, legal and financial consultation services, neuropsychological evaluations). Some services are provided by community agencies or service providers with which FSP does not have contracts. In 1987, FSP contracted for 25,510 hours of in-home respite, 1,946 days of day care, 59 hours of legal or financial consultation, 74 hours of neuropsychological patient evaluation, and 16 one-way transports (200).

An FSP staff member, usually the family consultant or social worker who originally assessed the family's needs, maintains ongoing contact with a family using FSP-recommended services (405). If respite services are involved, the contact person is the social worker who arranges the respite services and monitors the services at monthly intervals. An FSP staff member gives caregivers verbal and written instructions on how to use the services, and FSP's staff coordinates information about the caregiver's situation with the service provider. An FSP staff member telephones to make sure that families have been linked successfully with community agencies or services with which FSP does not have contracts.

At 6-month intervals, families receiving services are reassessed by the family consultant or social worker to determine what, if any, changes in their situation may warrant revising the plan of care and to measure the effectiveness of service interventions on the caregiver's well-being (405). If there is a significant change in the caregiver's or brain-impaired person's situation or if a major crisis occurs, families may be reassessed before the 6-month period has elapsed.

FSP uses various means to try to ensure the quality of services provided by or through the Bay Area Regional Resource Center (405). In addition to holding regular case conferences and performing 6-month reassessments, FSP sends family caregivers a client satisfaction survey. Respite providers—including home care agencies, day care programs, and inpatient respite facilities—are required to submit with their bid package information on licensing, staff qualifications, program services, internal quality assurance procedures, and insurance verification. FSP staff members visit respite providers to meet their staff and observe their programs before signing a contract. Similarly, FSP staff members screen attorneys and neuropsychologists for their expertise and sensitivity to the needs of caregivers of brain-impaired adults before FSP contracts for their services.

Public Education

FSP provides extensive public education to increase public and professional awareness of the needs of brain-impaired people and their caregivers (200). In its capacity as the Statewide Resources Consultant, FSP regularly distributes information letters and bulletins to a general mailing list of more than 15,000 individuals and groups throughout California and provides information and technical assistance to California's regional resource centers. It also distributes a quarterly newsletter with updated information on services, public policy, research, and available resources for brain-impaired adults and their caregivers. FSP maintains an updated speakers file of professionals and consumer advocates (200).

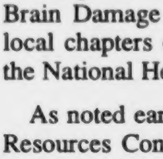
For professionals who deal with brain-impaired adults, including individuals with dementia, FSP offers training programs that cover topics ranging from patient management to legal and financial matters. FSP also publishes a bimonthly "Training Events Calendar," which includes information about training opportunities and upcoming State and national conferences (200).

For government agencies, service providers, and volunteer groups interested in developing new programs and services for brain-impaired adults and their families, FSP often provides technical assistance—e.g., training, consultation, and information. The organizations that FSP has helped include the Brain Damage Coalition of California, as well as local chapters of the Alzheimer's Association and the National Head Injury Foundation (199).

As noted earlier, in its capacity as the Statewide Resources Consultant, FSP conducts social policy research. Among the studies FSP has conducted are a study of publicly funded and third-party programs available to brain-impaired adults and their caregivers, a study of the cost of care of brain-impaired adults, and a study of employed caregivers of brain-impaired adults (200).

FSP also seeks to educate the public about brain impairment and related issues in its capacity as the Bay Area Regional Resource Center (199). The primary way it does this is through community forums and fact sheets, handbooks, and brochures.

Outreach



Although FSP conducts extensive public education programs, it does not have specific outreach procedures to identify brain-impaired adults or caregivers who need assistance but are unlikely to seek help on their own or to be referred to FSP by someone else. Brain-impaired adults who live alone and have no relative or friend to help them and overburdened caregivers who are not connected to a community agency or individual health or social service provider are unlikely to be reached by FSP.

To assist caregivers in rural areas, some of California's regional resource centers use an "outstationed" family consultant. For some rural families, the outstationed family consultant may be the only source of information and patient management assistance in the community (405).

Role in Allocating Services and Funding

FSP does not control access to, or funding for, services other than those (e.g., respite services) it makes available.

Summary

As an agency that might be designated to serve as the basis of a national system to link people with dementia to services, FSP offers many advantages:

- FSP is part of a well-developed, easily accessible statewide system that provides information and referrals to services for brain-impaired adults and their caregivers in California. As California's Statewide Resources Consultant, FSP maintains a statewide database of information about brain impairment, related caregiving problems, and service options for brain-impaired adults and their caregivers. As the Bay Area Regional Resource Center, it maintains comprehensive lists of services in each of the counties in its service area.
- FSP assesses the needs of some caregivers of brain-impaired adults who call the agency and recommends services that are provided either directly by FSP (e.g., short-term counseling, family consultation, long-term care planning, and caregiver support groups), by service providers under contract to FSP (e.g., legal and financial consultation, transportation, and respite services), or by other providers in the community.
- FSP follows up to ensure that brain-impaired adults and their caregivers receive the recommended services.
- FSP provides education and training for caregivers, professionals, and other individuals who deal with brain-impaired adults.

FSP is currently established only in California. If FSP were to be designated as the basis of a nationwide system to link people with dementia to services, it would have to be replicated throughout the country. FSP's programs have been imitated throughout California and informally by organizations that are developing services for people with dementia and their caregivers in other States, so replication throughout the country might be accomplished fairly easily.

Although FSP's functions and goals closely parallel those OTA finds essential for an effective system to locate and arrange services for people with dementia, most of the services provided by FSP focus on the needs of the caregivers of brain-impaired adults. In the absence of outreach procedures, people with dementia who live alone and have no caregiver to help them may not be identified by FSP and, as a result, may not be connected to the services they need.

REGIONAL ALZHEIMER'S DIAGNOSTIC AND ASSESSMENT CENTERS

In the past few years, some States have established regional Alzheimer's diagnostic and assessment centers. Although the names and functions of these centers vary from State-to-State, all the centers have certain things in common. They are all associated with medical centers. They all offer individuals suspected of having Alzheimer's disease or a related disorder a diagnosis and a comprehensive assessment by a multidisciplinary team that is knowledgeable about dementia, and they all develop a plan of care for each individual that typically includes recommendations regarding appropriate health care, long-term care, social, and other services. Some regional Alzheimer's diagnostic and assessment centers provide services such as medical treatment, psychiatric treatment, adult day care, caregiver education and training, and caregiver support groups, and some centers assist in locating and arranging services for their clients. Many of the centers also conduct biomedical and clinical research.

OTA has included regional Alzheimer's diagnostic and assessment centers in its analysis of agencies that might constitute a national system to link people with dementia to services for several reasons. One reason is that such centers are currently serving people with dementia. More importantly, however, the centers provide people who are suspected of having Alzheimer's or another dementing illness an accurate diagnosis and a comprehensive multidimensional assessment. Many diseases that cause dementia cannot be cured at present, but some can be cured or ameliorated if they are diagnosed accurately and treated correctly. Identifying these curable diseases is the first step in caring for people with dementia. Individuals who have a dementing disease that is not curable still may have other treatable conditions that exacerbate their dementia and make them less able to function independently and more difficult for their families and others to manage. A comprehensive evaluation can help to identify these potentially remediable conditions. Lastly, a comprehensive evaluation provides the information that is needed to match an individual with appropriate services.

Overview of the Agencies

At least 10 States have one or more regional Alzheimer's diagnostic and assessment centers (513). The regional Alzheimer's diagnostic and assessment centers in five States—California, Florida, Illinois, New Jersey, and Pennsylvania—are described in this section. Connecticut, Kentucky, Maryland, New York, and Ohio also have regional Alzheimer's diagnostic and assessment centers, and other States may have such centers as well. Detailed information about the centers in California, Florida, Illinois, New Jersey, and Pennsylvania is presented in this section to give a sense of some of the similarities and differences among existing centers. No implication is intended about the relative merits of the centers in these five States v. the centers in other States.

All the centers are quite new. California began developing its centers in 1984 (227), and the centers in other States have been established since then.

The regional Alzheimer's diagnostic and assessment centers in California, Florida, Illinois, New Jersey, and Pennsylvania all use a multidisciplinary team to provide diagnosis, comprehensive assessments, and other services for their clients. The composition of the team varies from center to center, but typically includes a physician (e.g., geriatric internist, neurologist, psychiatrist) and other professionals (e.g., clinical psychologist, social worker, nurse) (55,222,227,306,522).

In all five States, startup funding for the regional diagnostic and assessment centers came from a combination of State funds and public and private grants (55,220,225,364,599). Medicare, Medicaid, and private insurance cover some of the costs of diagnosis, assessment, and medical or psychiatric treatment provided by some of the centers. In addition, all of the centers derive some of their funding from client fees. All of the States but Pennsylvania have continued to provide funds for their centers' operating costs (14,364).

California's Alzheimer's Disease Diagnostic and Treatment Centers: California has a statewide system of nine centers called "Alzheimer's Disease Diagnostic and Treatment Centers." The nine centers and their locations are:

- Program for Alzheimer's Disease Care and Education, University of California/Langley Porter Psychiatric Institute in San Francisco;
- University of California, Davis-Northern California Alzheimer's Disease Center, Alta Bates-Herrick Hospital in Berkeley;
- Alzheimer's Disease Diagnostic and Treatment Center, University of California/Davis Medical Center in Sacramento;
- Alzheimer's Disease Diagnostic and Treatment Center, University of Southern California/St. Barnabas Senior Center in Los Angeles;
- Southern California Alzheimer's Disease Diagnostic and Treatment Center, University of Southern California/Rancho Los Amigos Medical Center in Downey;
- Alzheimer's Disease Diagnostic and Treatment Center, University of California/San Diego Medical Center in San Diego;
- Alzheimer's Disease Center, Stanford University/Palo Alto Veterans Administration Medical Center in Palo Alto;
- Alzheimer's Disease Diagnostic and Treatment Center, University of California, San Francisco/Fresno Veterans Administration Medical Center in Fresno; and
- Alzheimer's Disease Diagnostic and Treatment Center, University of California, California College of Medicine/Valley Medical Center in Irvine (335).

The functions of the nine California centers are described in box 8-I. In 1984, the California legislature appropriated $1 million to initiate the statewide system of diagnostic and treatment centers (225). The legislature has provided funding for the centers' operation each year since then. In fiscal year 1988-89, $2.9 million was appropriated for this purpose (14).

Florida's Memory Disorder Clinics: Florida has four regional Alzheimer's diagnostic and assessment centers called "Memory Disorder Clinics." The clinics were established as part of the Florida Alzheimer's Initiative enacted in 1985 (214). The memory disorder clinics are located at the following sites:

- Suncoast Gerontology Center at the University of South Florida Medical School in Tampa,
- Center on Adult Development and Aging at the University of Miami Medical School in Miami,
- Wein Center at the Mount Sinai Medical Center in Miami, and
- Shands Teaching Hospital at the University of Florida Medical School in Gainesville (222).

The clinics in Tampa and Miami have multilingual staff and print their publications in both English and Spanish (222).

All of Florida's memory disorder clinics offer individuals with memory impairment a diagnosis and assessment by a multidisciplinary team, a plan of care that includes recommendations about needed medical, psychiatric, and other treatment, and referrals to community service providers (222). With the patient's and/or family's permission, the clinics forward a report of the diagnosis and recommended plan of care to the patient's primary care physician and consult with the primary care physician regarding ongoing medical management.

Florida's memory disorder clinics provide extended medical and psychiatric treatment for some of their patients (222). The clinics also provide caregiver support groups and counseling for families about caregiving and legal and financial issues.

In 1985, the Florida legislature appropriated $500,000 to establish the four Memory Disorder Clinics (220). In fiscal year 1988-89, the legislature provided nearly $0.9 million to operate the clinics (14). The clinics are eventually supposed to support themselves through an Alzheimer's Disease Trust Fund consisting of monies from gifts, grants, and other sources; as of 1988, however, Florida was having difficulty expanding its system of memory disorder clinics statewide because of funding limitations (302).

Illinois' Regional Alzheimer's Disease Assistance Centers: Illinois has two regional diagnostic and assessment centers called "Regional Alzheimer's Disease Assistance Centers." These centers (see

Box 8-I—California's Alzheimer's Disease Diagnostic and Treatment Centers

In 1984, the California legislature passed a law mandating the establishment of Alzheimer's disease diagnostic and treatment centers. Subsequently, contracts for the development of the centers were awarded to nine university schools of medicine in various parts of the State. Six centers were established in 1985, and three more began operating in 1989.

California's nine Alzheimer's Disease Diagnostic and Treatment Centers are currently required by the State:

1. to provide diagnostic and treatment services for Alzheimer's patients, including those under age 65;
2. to conduct research to discover the cause of, and treatment for, Alzheimer's disease;
3. to provide training, consultation, and education to caregivers of Alzheimer's disease patients;
4. to increase the training of health care professionals about Alzheimer's disease;
5. to develop a uniform data system to compile demographic, medical, and service use information for each patient seen at the centers; and
6. to reevaluate all of their Alzheimer's patients annually.

The nine centers offer their patients a comprehensive evaluation that typically includes a medical, neurological, psychiatric, psychological, and social assessment and may also include a dental, audiological, and podiatric examination and a nutritional evaluation. If there are concerns about whether a patient can be cared for effectively at home, a social worker or nurse practitioner assesses the person's home environment. Following the assessment, members of the center's multidisciplinary team discuss options for the patient's care and meet with the patient and/or the patient's family to develop a plan of care. The services the centers offer their patients vary but can include nursing, social work, pharmacy, occupational therapy, and physical therapy. Three centers (in Downey, San Diego, and Berkeley) have adult day care programs.

California's Alzheimer's Disease Diagnostic and Treatment Centers refer their patients to community services, but they generally do not provide case management unless the staff believe that a patient and his or her family require special assistance. An exception is the St. Barnabas Senior Center in Los Angeles, which provides extensive case management for some of its clients.[1]

In addition to conducting research on Alzheimer's disease, the staff at California's Alzheimer's Disease Diagnostic and Treatment Centers give lectures and presentations to community groups to educate them about Alzheimer's disease and related issues. In addition, the centers offer caregiver training and support groups for family caregivers and education and training programs for health care and social service professionals and other service providers. The centers offer academic courses and residency internships to physicians, postdoctoral students, and graduate students in social work, nursing, psychology, public health, dentistry, and associated fields.

Some of the Alzheimer's Disease Diagnostic and Treatment Centers have adapted their programs to meet the special needs of individuals with dementia in their service area. For instance, the center in San Diego is developing culturally and linguistically appropriate neuropsychological tests to more effectively serve the large Spanish-speaking population in San Diego County. The center in Sacramento has worked with community agencies and area physicians to develop services that can be accessed locally because of its rural service area.

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[1] The case management provided by the Alzheimer's Disease Diagnostic and Treatment Center at the St. Barnabas Senior Center in Los Angeles is discussed later in this section.

SOURCES: P.J. Fox, D.A. Lindeman, and A.E. Benjamin, *Status of Alzheimer's Disease Diagnostic and Treatment Centers and Alzheimer's Disease Research Grants in California* (San Francisco, CA: University of California, Institute for Health and Aging, January 1986); P.J. Fox, D.A. Lindeman, and A.E. Benjamin, *Evaluation of Alzheimer's Disease Diagnostic and Treatment Centers in California: 1987 Project Year* (San Francisco, CA: University of California, Institute for Health and Aging, January 1988); D.A. Lindeman, administrative director, Northern California Alzheimer's Disease Center, personal communication, Nov. 20, 1989.

box 8-J) provide a comprehensive medical evaluation for individuals who are thought to have Alzheimer's disease, develop a plan of care for each individual, and assist the individuals and their caregivers in locating and arranging services in their communities (349). One center at Rush-Presbyterian-St. Luke's Medical Center serves the Chicago metropolitan area. The other center at Southern Illinois University School of Medicine serves the predominately rural, downstate counties (349).

The Illinois legislature appropriated $170,000 to cover startup costs for the two centers in 1987 (55). In fiscal year 1989, the legislature appropriated $1.2 million for the operating costs of the centers (14).

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Box 8-J—Illinois' Alzheimer's Disease Assistance Centers

Illinois has two Alzheimer's Disease Assistance Centers associated with medical schools—one in Chicago and one in Springfield—that provide diagnosis and assessment for people with Alzheimer's disease and other dementing illnesses. The centers provide their patients comprehensive evaluations consisting of a general physical and neurological examination, neuropsychological testing, laboratory tests, and psychiatric and psychosocial evaluation. After a consultation with the patient, the patient's family, and the evaluation team, the team's social worker assists the family in arranging medical and social services for the patient and helps the family find a support group and/or family counseling services.

Medical followup generally consists of consultation with each patient's primary care physician and the provision of semi-annual reevaluations. As the number of clients served by the Southern Illinois University Center has increased, the center has devoted more resources to providing ongoing case management: the center's social worker and other staff members maintain at least monthly contact with patients who require special attention.

In addition to its current services, each of the Alzheimer's Disease Assistance Centers is developing a system of hospitals or medical centers (known as "primary providers") to function as local sites for diagnosis and treatment for Alzheimer's patients. Each center is also developing a system of community health care, mental health, and social service providers to which Alzheimer's patients and their families can be referred. Each center has compiled a county- by-county database of available community services for its region.

SOURCE: M. Barringer, clinical coordinator, Southern Illinois University School of Medicine, Alzheimer's Center, Springfield, IL, personal communications, Feb. 2, 1988, Aug. 19, 1988, and Nov. 5, 1988.

New Jersey's Regional Alzheimer's Diagnostic and Assessment Centers: New Jersey has two regional Alzheimer's diagnostic and assessment centers:

- Institute for Alzheimer's Disease and Related Disorders, established in 1985 at the Robert Wood Johnson Medical School in Piscataway; and
- Alzheimer's Evaluation Program, established in 1986 at the University of Medicine and Dentistry of New Jersey, School of Osteopathic Medicine, in Stratford.

New Jersey's two Alzheimer's diagnostic and assessment centers work in conjunction with eight State-funded geriatric assessment programs located in medical centers throughout the State to provide a coordinated system of diagnosis and assessment for people suspected of having Alzheimer's disease (272). The centers rely on their patients' primary care physicians to provide ongoing medical treatment (599). Both of the centers provide their patients with referrals to community services, and both centers offer consultation, education, and training for family caregivers and service providers.

One of New Jersey's centers, the Institute for Alzheimer's Disease and Related Disorders in Piscataway, provides long-term case management for its clients, if they need it (272). The center in Piscataway also provides caregiver support groups and dementia-specific adult day care and serves as a clearinghouse for information about Alzheimer's disease for the general public (599). The center maintains a statewide directory of services for Alzheimer's patients (599).

In 1986, the New Jersey legislature appropriated $500,000 to fund the two centers' startup costs (599). In fiscal year 1989-90, the New Jersey legislature appropriated $615,000 for their operating costs (14).

Pennsylvania's Diagnostic and Evaluation Centers for Alzheimer's Disease: Pennsylvania has 11 regional Alzheimer's diagnostic and assessment centers called "Diagnostic and Evaluation Centers for Alzheimer's Disease" that replicate a model program developed by the Harrisburg Institute of Psychiatry under a contract with the Pennsylvania Department of Aging (306). These 11 centers, all established since 1985, augment the services provided by 21 geriatric assessment programs in the State. Pennsylvania's 11 Diagnostic and Evaluation Centers are located at the following sites:

- Sharon General Hospital in Sharon,
- Altoona Hospital in Altoona,
- Medical Center of Beaver County in Beaver,
- Soldiers and Sailors Memorial Hospital in Wellsboro,
- Wilkes-Barre General Hospital in Wilkes-Barre,

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- Western Pennsylvania Hospital in Pittsburgh,
- Community Health Services in Quakertown,
- Hamot Medical Center in Erie,
- Franklin Regional Medical Center in Franklin,
- Divine Providence Hospital in Williamsport, and
- Moses Taylor Hospital in Scranton (306).

At any of the 11 centers, a patient suspected of having Alzheimer's disease can get a comprehensive evaluation by a multidisciplinary team that typically consists of a psychiatrist, physician, clinical psychologist, social worker, and registered nurse (306). The team submits its findings and a recommended plan of care to the patient's primary physician who retains responsibility for the patient's ongoing medical care. If a patient has no primary care physician, the team's social worker assists the patient in obtaining one. The team's physician may monitor a patient for a short period of time (weeks to months) to supervise the patient's medications. The team's social worker educates family caregivers about Alzheimer's disease and related issues, trains caregivers to care for the patient, provides family therapy, and refers families to Alzheimer's support groups and health care and social services in the community.

The Pennsylvania legislature appropriated $500,000 in fiscal year 1985 for an Alzheimer's disease initiative. Included as 1 of the initiative's 10 components was provision for technical assistance by the Harrisburg Institute of Psychiatry for the development of the Diagnostic and Evaluation Centers for Alzheimer's Disease (650). Now that the 11 centers are established, they are expected to operate without State funding (364).

Who Is Served

The regional Alzheimer's diagnostic and assessment centers in California, Florida, Illinois, New Jersey, and Pennsylvania serve anyone suspected of having Alzheimer's disease or a related disorder. Most clients are referred to the regional centers by hospitals, primary care physicians, family members, and community organizations, but some clients are self-referred (222,349,364,522,227). The number of people served by individual centers varies; Pennsylvania's centers evaluate an average of three new patients a month (364), whereas Illinois' centers evaluate an average of 30 patients a month (349). Because dementing disorders are most prevalent among elderly people, the majority of people served by the centers are elderly, but they also serve younger people.

Linking Functions

Information and Referral

All of the regional Alzheimer's diagnostic and assessment centers in California, Florida, Illinois, New Jersey, and Pennsylvania provide their clients with information and referrals to health care, long-term care, social, and other services and have a social worker on their multidisciplinary team to do this (55,222,227,306,599). Some regional centers follow-up with a phone call or postcard to see whether their clients obtained the services to which they were referred (55). California's centers are gathering data now to determine whether their clients use the services to which they are referred (334,460).

All of the Alzheimer's diagnostic and assessment centers in the five States are capable of providing information and referrals for people other than their own clients, but most of the centers do not consider providing information and referrals to the general public as one of their primary functions. The exceptions are Illinois' center in Springfield and New Jersey's center in Piscataway, each of which operates an Alzheimer's-specific information and referral program with a toll-free number for the general public (600,347).[17]

The centers in California, Florida, Illinois, New Jersey, and Pennsylvania either have access to or are currently developing comprehensive lists of community resources for Alzheimer's patients and their caregivers. California's centers have a uniform data system to compile information about their clients, including information about the types of services the clients use. This data system is compatible with that of California's regional resource centers for brain-impaired adults (225).[18] New Jersey's Institute for

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[17] In California and Pennsylvania, agencies other than the regional Alzheimer's diagnostic and assessment centers are the primary sources of Alzheimer-specific information and referrals and operate statewide telephone information and referral programs.

[18] California's regional resource centers for brain-impaired adults patterned after the Family Survival Project are discussed in the section on the Family Survival Project in this chapter and in the section on California's linking programs in ch. 7.

Alzheimer's Disease and Related Disorders in Piscataway is developing a similar database (272).

Illinois' Regional Alzheimer's Disease Assistance Centers are in the process of developing a catalog of service providers in each county of their regions (349). In Pennsylvania, the Department of Aging did a survey by county of hospitals, State agencies, and community service providers, and the survey results are being used to develop a database of statewide services to be used by Pennsylvania's Diagnostic and Evaluation Centers for Alzheimer's Disease (616).

Case Management

All of the regional Alzheimer's diagnostic and assessment centers provide their clients with a multidisciplinary assessment and develop a plan of care for them. The extent to which regional centers perform the other core functions of case management (e.g., arrange and coordinate needed services, monitor and evaluate the services delivered, and reassess the client's situation as the need arises) varies greatly among individual centers. Moreover, some regional centers limit their case management activities to arranging medical services.

California's Alzheimer's Disease Diagnostic and Treatment Centers typically do not arrange and coordinate nonmedical services for their clients unless a client or his/her family requires special assistance (334). The center at St. Barnabas Senior Center in Los Angeles is the exception to this rule; it provides many of its clients with extensive case management (225,227). The majority of St. Barnabas Senior Center's clients are isolated, poor, elderly people, many of whom have no family caregiver. St. Barnabas' five social workers select individuals with dementia from the senior center's clientele and screen them for admission to the Alzheimer's Disease Diagnostic and Treatment Center's program. Following a comprehensive assessment, the social workers arrange and coordinate in-home and other community services for the individuals. The Alzheimer's Disease Diagnostic and Treatment Center also operates a home care program that provides shopping, transportation, and companion services for elderly dementia patients. St. Barnabas Senior Center has a money management program, which is available to individuals in the Alzheimer's Disease Diagnostic and Treatment Center's program, and provides help in bill paying or acts as power of attorney or conservator for individuals incapable of managing their own funds (227).

Florida's Memory Disorder Clinics develop a plan of care and refer their clients to services in the community, but they generally do not arrange the services (222). Ongoing contact with a client is limited to a formal medical reassessment every 6 months. The reassessment includes a followup family conference, where unmet needs can be identified and referrals to appropriate services can be made.

Illinois' two regional Alzheimer's disease assistance centers use social workers and nurses to help clients and their families arrange and coordinate community services (55). The social workers and nurses follow-up by postcard or phone call to see that clients are satisfied with the services and maintain at least monthly contact with patients who require special attention. Clients receive semiannual or annual medical reevaluations that include a family conference where it can be determined whether the client and family are receiving the services they need.

New Jersey's Institute for Alzheimer's Disease and Related Disorders in Piscataway offers ongoing case management for all of its clients who need it (272). New Jersey's Alzheimer's Evaluation Program in Stratford, which serves a predominately rural southern part of the State where families must travel a long distance to the center, refers its clients to local agencies for case management.

Pennsylvania's Regional Diagnostic and Evaluation Centers for Alzheimer's Disease rely on a patient's primary physician to carry out the recommended plan of medical care. As noted earlier, if a patient has no primary physician, the center's social worker assists the patient in obtaining one. The center's social worker also refers patients and their families who need social services to agencies in the community, but the social workers rely on the community agencies to provide extended case management for patients and their families who need it.

Public Education

To inform the public about the availability of their services, the five States' regional Alzheimer's diagnostic and assessment centers distribute written materials about dementia and the services they offer for people with Alzheimer's disease and their caregivers. The staff of some of the centers also participate in community meetings and other public forums to educate people about dementia and about potentially helpful services for people with dementia.

Outreach

Most regional Alzheimer's diagnostic and assessment centers do not have outreach procedures to identify people with dementia who need assistance but are unlikely to contact a center on their own or to be referred. At least some of the centers do serve people with dementia who live alone and have no family caregiver, however. In the period from June 1985 to June 1987, 22 percent of the 452 people with dementia who were seen by California's Alzheimer's Disease Diagnostic and Treatment Centers lived alone, and 10 percent had no caregiver (227). Of those seen by the center at St. Barnabas Senior Center, 80 percent lived alone, and more than 20 percent had no caregiver. Individuals who live alone and have no caregiver may be referred to an Alzheimer's diagnostic and assessment center by a physician, another health care or social service professional, a community agency, or another source.

Some regional Alzheimer's diagnostic and assessment centers have mobile assessment units to reach patients who live in remote areas. New Jersey's Alzheimer's Evaluation Program in Stratford operates a mobile assessment van that travels throughout the predominately rural southern part of the State to minimize transportation difficulties for the families of Alzheimer's patients. Likewise, one of the regional Alzheimer's Diagnostic and Evaluation Centers in Pennsylvania has developed a "Project Concern" program in which health care professionals travel in a specially equipped mobile van to rural areas of the State to provide health education and diagnostic screening tests. California's Alzheimer's Disease Diagnostic and Treatment Centers are developing mobile geriatric assessment units to reach patients living in remote areas of the State.

Role in Allocating Services and Funding

The regional Alzheimer's diagnostic and assessment centers in California, Florida, Illinois, New Jersey, and Pennsylvania do not control access to services or funding for services other than those they provide.

Summary

As agencies that might be designated to constitute a national system to link people with dementia to services, regional Alzheimer's diagnostic and assessment centers offer the following advantages:

- Regional Alzheimer's diagnostic and assessment centers have a multidisciplinary staff that includes professionals who are specifically knowledgeable about dementia.
- Regional Alzheimer's diagnostic and assessment centers provide individuals suspected of having Alzheimer's disease a comprehensive evaluation that may reveal a treatable cause for their dementia or other treatable conditions that are exacerbating their dementia and reducing their functional ability.
- Regional Alzheimer's diagnostic and assessment centers provide comprehensive assessments that may help match individuals with appropriate services.
- Regional Alzheimer's diagnostic and assessment centers provide their clients with referrals to community services, and some centers function as formal sources of Alzheimer-specific information and referrals for the general public.
- Some regional Alzheimer's diagnostic and assessment centers provide short-term case management to arrange and coordinate services for their clients, and a few centers provide extended case management.
- Since regional Alzheimer's diagnostic and assessment centers provide diagnosis, they are the first point at which some people with dementia and their families come in contact with the so-called service system; as such, the centers help these patients and their families identify appropriate services relatively early in the patient's disease. Similarly, since many of the centers reevaluate patients at regular intervals, they can be sites for intermittent referrals and assistance in arranging services for patients and families.
- Regional Alzheimer's diagnostic and assessment centers are already established in some States.

Despite these advantages, designating regional Alzheimer's diagnostic and assessment centers as the basis of a national system for linking people with dementia to services would have several drawbacks. One obvious drawback is that most States do not have such centers. A second drawback is that most of the existing centers do not consider providing information and referrals to the general public as one of their primary functions. Furthermore, although all the centers refer their clients to services, many of them do not follow-up to make sure that the clients obtain the services.

At least some regional Alzheimer's diagnostic and assessment centers have clients who live alone and have no family member or other informal caregiver. On the other hand, most of the existing centers do not have outreach procedures to identify people with dementia who are unable to seek help on their own and have no one to help them. Likewise, most of the existing centers do not provide the extended case management that may be needed to arrange, coordinate, and monitor services for such people. If regional Alzheimer's diagnostic and assessment centers were designated to constitute a national linking system for people with dementia, most of the existing centers would have to expand their information and referral, case management, and outreach programs significantly.

Finally, it should be noted that some families of individuals with dementia do not think of the individual as a "person with dementia;" this is probably especially likely if the individual has physical impairments in addition to his or her dementia. These families are unlikely to contact a regional Alzheimer's diagnostic and assessment center for help. Likewise, people who perceive a stigma associated with a diagnosis of Alzheimer's disease may be unwilling to contact a regional Alzheimer's diagnostic and assessment center.

HOSPITAL-BASED GERIATRIC ASSESSMENT PROGRAMS

Hospital-based geriatric assessment programs are special hospital programs that use a multidisciplinary team to evaluate elderly patients with complicated medical or psychiatric problems and to develop a coordinated plan of care (848). Although hospital-based geriatric assessment programs differ from one another, they are all designed to provide a comprehensive assessment of a patient's physical, mental, emotional, behavioral, functional, social, and financial status and to identify both problems and strengths of the patient (723). Some hospital-based geriatric assessment programs also provide medical and psychiatric treatment and rehabilitative services, and many link their patients to other services in the community. A nationwide survey of nearly 7,000 hospitals conducted in 1987 by the American Hospital Association found that about 1,400 hospitals had a geriatric assessment program (532).

OTA has included hospital-based geriatric assessment programs in its analysis of agencies that might constitute a national system to link people with dementia to services for two reasons. The most important reason is that these programs provide comprehensive, multidimensional patient assessments that can improve diagnostic accuracy, identify potentially treatable diseases and conditions, and help to define a patient's service needs. As noted in the previous section, many diseases that cause dementia cannot be cured at present, but some can be cured or ameliorated if they are diagnosed accurately and treated correctly. Identifying these curable diseases is the first step in caring for people with dementia. Individuals who have dementing diseases that are not curable still may have other treatable illnesses and conditions that exacerbate their dementia and make them less able to function independently and more difficult for their families and others to manage. If these illnesses and conditions are detected and treated effectively, an individual's overall functioning may improve, and his or her service needs may be reduced. Lastly, even if an individual has an incurable dementing disease and no treatable illnesses or conditions that are exacerbating his or her dementia, a comprehensive, multidimensional assessment provides information that is needed to match the individual with appropriate services.

The second reason that OTA has included hospital-based geriatric assessment programs in its analysis of agencies that might constitute a national system to link people with dementia to services is that the programs are associated with hospitals. Hospitals exist in most communities. Many people are familiar with hospitals and accustomed to relying on hospitals for help with medical problems (89). Moreover, hospitals are available on a round-the-clock basis, 7 days a week, and they are usually centrally located and accessible by public transportation. Not all hospitals have a geriatric assessment program, but it is likely that if reimbursement were available through Medicare or other funding sources, many more hospitals would establish such programs.

Overview of the Agencies

Hospital-based geriatric assessment programs include both inpatient and outpatient programs. The inpatient programs typically provide more intensive evaluation and treatment and serve elderly patients with illnesses that necessitate hospitalization (726). The outpatient programs typically serve elderly patients who do not need hospitalization or inpatient testing and who can be evaluated and treated on an outpatient basis.

Both inpatient and outpatient geriatric assessment programs use multidisciplinary teams to perform comprehensive patient assessments. The teams typically include a physician, a nurse, and a social worker, and, if not included on the core team, a wide variety of other health care professionals (e.g., psychiatrists, psychologists, dietitians, pharmacists, occupational therapists, and physical therapists) who are available for consultation (272,394,907). Although the size and composition of geriatric assessment teams vary, the teams typically have staff who are knowledgeable about dementia (12,701,726,907).

Rubenstein has identified four major types of inpatient and outpatient hospital-based geriatric assessment programs:

- inpatient geriatric specialty units,
- inpatient geriatric consultation services,
- outpatient geriatric services, and
- inpatient and outpatient geropsychiatry services (723).

Inpatient geriatric specialty units are the most common type of geriatric assessment program (723). They generally offer hospitalized patients a comprehensive assessment by a multidisciplinary team, a comprehensive plan of care, treatment, and recommendations for care following hospital discharge. Inpatient geriatric specialty units are of three main kinds: 1) subacute geriatric assessment units, 2) geriatric rehabilitation units, and 3) special-emphasis acute care units. The first kind, subacute geriatric assessment units, typically provide subacute treatment and rehabilitation for a carefully targeted group of frail elderly patients (723). Most subacute geriatric assessment units are part of the Veterans Administration (VA) system, which, as of 1989, had 87 such units (917). A subacute geriatric assessment unit at the VA medical center in Sepulveda, CA, is described in box 8-K.

The second kind of inpatient geriatric specialty unit—geriatric rehabilitation units—provide intensive rehabilitative services to hospitalized patients (723). Some units of this type exclude people with dementia on the grounds that they are incapable of benefiting from rehabilitative services (35).

The third kind of inpatient geriatric specialty unit (special-emphasis acute care units) are acute care hospital wards that specialize in treating certain physical and mental problems that are common in elderly people (723). Such units have a multidisciplinary team trained to identify and treat these problems.

The second major type of hospital-based geriatric assessment program, *inpatient geriatric consultation services*, consist of freestanding teams of health care professionals who visit hospitalized patients and perform comprehensive assessments to identify the patients' medical and psychiatric impairments (328,455,723). Staffing patterns of inpatient geriatric consultation teams reflect the goals and the resources of the hospital in which the team functions; most have physicians (house staff and/or faculty geriatricians), nurses, and social workers, but they usually do not have all the disciplines represented on the staff of an inpatient geriatric specialty unit (723,914). Ordinarily, an assessment by a geriatric consultation team is performed at the request of a patient's primary physician (328, 723,914). The consultation team makes recommendations and works with the primary physician and other hospital staff to implement the recommendations, but the team has no control over patient management, nursing, or rehabilitative services (107,914).

The third major type of hospital-based geriatric assessment program, *outpatient geriatric services*, are hospital-affiliated clinics that use a multidisciplinary team to provide a comprehensive assessment to elderly people who come or are referred to the clinic (723). Some outpatient geriatric services also provide other services, depending on their staff's expertise and the needs of their clientele. An outpatient geriatric clinic associated with a hospital in Rochester, New York, is described in box 8-L.

Box 8-K—An Inpatient Subacute Geriatric Assessment Unit: The Geriatric Evaluation Unit at the Sepulveda VA Medical Center in Sepulveda, California

In June 1979, the VA Medical Center in Sepulveda, California, opened an inpatient Geriatric Evaluation Unit with 15 beds on a 29-bed subacute care hospital ward. The unit is staffed full time by a multidisciplinary team consisting of a faculty geriatrician, a physician's assistant, a geriatric fellow, a medical intern, and geriatric nurses; part-time staff include a social worker, psychologist, dietitian, pharmacist, occupational therapist, and physical therapist.

The Geriatric Evaluation Unit's goals are to provide elderly patients with:

1. a comprehensive assessment by a multidisciplinary team;
2. short-term, goal-oriented therapy and rehabilitation; and
3. arrangements for followup care after hospital discharge.

Patients are admitted to the Geriatric Evaluation Unit from an acute inpatient ward or from the outpatient department of the Sepulveda VA Medical Center. To be eligible for admission to the unit, patients must be over age 65 and have medical, functional, or psychosocial problems that interfere with living at home. Patients are denied admission to the unit if they are in the terminal phase of a disease (e.g., cancer), require acute care, or have end-stage dementia and no social support system to prevent their placement in a nursing home.

The focus of the first week of a patient's stay in the Geriatric Evaluation Unit is typically on assessing the patient's needs and planning treatment. The focus of the subsequent 3 or 4 weeks is usually on providing treatment and rehabilitation. Taking into account the nature and extent of the patient's therapeutic progress, the multidisciplinary team develops a plan for the medical care of the patient following discharge from the hospital. Patients who have been discharged are eligible to be seen regularly in the geriatric followup clinic, usually by the same physician or physician's assistant who cared for them on the Geriatric Evaluation Unit.

SOURCE: L.Z. Rubenstein, K. Josephson, G.D. Wieland, et al., "Geriatric Assessment on a Subacute Hospital Ward," *Clinics in Geriatric Medicine*, L.Z. Rubenstein, L.J. Campbell, and R.L. Kane (eds.) (Philadelphia, PA: W.B. Saunders Co., 1987).

Patients of outpatient geriatric services are generally self-referred or referred by family members, community agencies, or physicians (549,907). Patients who are referred by their primary physician typically remain under the direct care of the physician. Some observers have noted that physicians are more likely to refer patients to outpatient geriatric services for psychosocial problems than for medical problems (549,909). These observers stress that geriatric assessment includes the evaluation of both medical and psychosocial problems and that there is a need to educate physicians to this effect (549,909).

The fourth major type of hospital-based geriatric assessment program, *geropsychiatry services*, exist specifically to serve elderly people with psychiatric problems. Geropsychiatry services are found in both inpatient and outpatient settings. An outpatient geropsychiatric clinic that serves elderly people in Seattle, Washington, is described in box 8-M.

Inpatient and outpatient geropsychiatry services provide elderly people with a comprehensive assessment by a multidisciplinary team that usually includes a psychiatrist and may include a psychologist (12,706). Inpatient units offer pharmacologic, psychotherapeutic, and behavioral interventions in a hospital setting where the patient's physical and mental condition can be closely monitored. The professionals on the multidisciplinary team usually participate actively in discharge planning for the patients they evaluate. Outpatient geropsychiatric clinics typically provide their clients with a comprehensive, multidimensional assessment and case management and link the clients and their caregivers to community services (706).

The costs of a hospital-based geriatric assessment vary, depending in part on the setting and composition of the assessment team. The average cost of an assessment is often much less in an outpatient program than an inpatient program (703,910). The inclusion of psychiatrists or other specialists as core members of an outpatient geriatric assessment team raises the cost of some outpatient programs, however (493,703).

The costs of a hospital-based inpatient or outpatient geriatric assessment per se are not covered by most third-party payers (379,722). Typically, Medicare, Medicaid, and private insurers cover physicians' services and lab tests associated with diagno-

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Box 8-L—An Outpatient Geriatric Service: The Geriatric Ambulatory Consultation Service at Monroe Community Hospital in Rochester, New York

The Geriatric Ambulatory Consultation Service affiliated with Monroe Community Hospital in Rochester, New York, is an outpatient clinic that provides comprehensive geriatric assessments. About one-third of the 131 elderly patients who received geriatric evaluations at the clinic between May 1983 and April 1984, had a dementing illness.

When someone calls the Geriatric Ambulatory Consultation Service, he or she is interviewed on the phone by a specially trained registered nurse. The nurse determines how urgent the situation is and what consultative expertise is necessary to address the problem and then arranges the necessary clinic appointments. The nurse is familiar with services provided by other professionals and agencies in the community and, in some cases, refers callers to these services.

At the initial clinic visit, a patient receives either a simple geriatric assessment or a full-team comprehensive assessment. Members of the multidisciplinary consultation team include a physician, a nurse, and a social worker. A psychiatrist is available two times a week to assess patients with psychiatric or behavioral problems. After the initial evaluation, the team may call on additional health care specialists for consultations, if needed.

After each clinic session, the members of the consultation team hold a conference to discuss each new patient. A plan of care is developed to meet the needs of each patient and the patient's family. The consultation team's social worker often contacts community agencies to arrange services for the patient or the patient's family and, when necessary, accompanies the family to case conferences with community agencies to discuss the patient and family's needs.

Followup visits at the clinic are scheduled as necessary to complete additional diagnostic procedures, to reevaluate the plan of care, and to review the patient's progress. Most patients require four followup visits. Conferences are often held with family members to refine and modify the plan of care. Home visits are provided to individuals who require such visits because of the complexity of their health care needs or questions about their home environment.

SOURCES: M.E. Williams, "Outpatient Geriatric Evaluation," *Clinics in Geriatric Medicine*, L.Z. Rubenstein, L.J. Campbell, and R.L. Kane (eds.) (Philadelphia, PA: W.B. Saunders Co., 1987); M.E. Williams and T.F. Williams, "Evaluation of Older Persons in the Ambulatory Setting," *Journal of the American Geriatrics Society* 34(1):37-43, 1986.

sis, but do not cover the services provided by nonphysician professionals (e.g., nurses and social workers) involved in the assessment process (493,701,703,722). Whatever costs are not covered by insurance are borne either by the patient or by the hospital with which the geriatric assessment program is affiliated (379,493).

Hospital-based geriatric assessment programs of various types are an established part of the health care systems of several countries (e.g., Great Britain, Sweden, and Israel) (722). Although such programs have been developing in the United States for the past 15 years, growth in the number of geriatric assessment programs has been slower here than in countries that have a national health care system to coordinate their financing and development (722).

Who Is Served

Geriatric assessment programs generally target elderly people with potentially remediable medical or psychiatric problems who may be at risk of premature or inappropriate institutionalization (394, 848). One commentator estimates that these "at-risk" elderly people constitute between 5 and 10 percent of hospitalized elderly patients and an undetermined percentage (perhaps 2 to 5 percent) of unhospitalized elderly people (722).

Some hospital-based geriatric assessment programs accept only elderly people who are considered to be at risk of nursing home placement (727). Other programs accept people primarily with psychiatric problems. Some programs exclude elderly people with acute illnesses; some exclude elderly people who are terminally or chronically ill (726); and some exclude people who are disruptive or who do not have the potential to be rehabilitated (35,726).

Very little information is available about the number of people with dementia who are served by geriatric assessment programs, but some types of geriatric assessment programs appear to be more likely than other types to serve people with demen-

Box 8-M—An Outpatient Geropsychiatric Clinic: The Geriatric and Family Services Clinic at the University of Washington Hospital in Seattle, Washington

The Geriatric and Family Services Clinic, located at the University of Washington Hospital Medicine Clinic, is an outpatient clinic that provides psychiatric, medical, and social evaluation of mentally impaired older persons, recommends appropriate treatment for them, and provides support and practical advice to their families. The evaluation generally entails a minimum of three, but typically four, visits to the clinic.

At the initial clinic visit, a psychiatrist or psychologist meets with the patient and family members (separately and together) to observe family dynamics, obtain the patient's psychiatric history, and formulate a diagnosis; a nurse and/or occupational therapist assesses the patient's day-to-day functioning and suggests ways to strengthen the patient's capabilities. At subsequent clinic visits, an internist or family physician examines the patient to identify and treat reversible causes of dementia, and, when needed, a psychologist administers additional tests to assess the patient's memory and intellectual functioning. If feasible, a social worker makes a home visit to gather information on the patient's home environment, family, etc. An architect may accompany the social worker on the home visit to inspect the patient's home and suggest physical changes to help the patient function better at home.

Following the elderly patient's visits to the clinic and the home visit, the multidisciplinary team holds a conference to consolidate findings and develop recommendations in 11 specified areas:

- housing and living situation,
- food and nutrition,
- self care,
- physical health,
- household tasks,
- emotional and mental factors,
- financial matters,
- transportation,
- day-to-day routine,
- family stress caused by a patient, and
- patient's interference with family members' work or other activities.

Using the notes from this conference, the staff prepares treatment recommendations and discusses them with the patient and the patient's family. The suggestions may include strategies such as starting medication; stopping medication; counseling for the patient, family, or both; use of community resources; behavior modification; and environmental manipulation. The clinic provides followup medical treatment as needed. The multidisciplinary team attempts to coordinate care with the patient's primary physician and other health care and social service professionals. Generally, one-quarter to one-half of the patients receive ongoing medical case management from the clinic.

At least four times a year, the clinic offers families of patients structured group sessions, at which members of the multidisciplinary team discuss various aspects of mental impairment, and families are given the opportunity to express feelings and discuss caregiving problems. The multidisciplinary team is also available for 10- to 15-minute telephone consultations whenever the family needs practical advice or help in warding off a crisis.

SOURCE: B.V. Reifler, E.B. Larson, and L. Teri, "An Outpatient Geriatric Psychiatry Assessment and Treatment Service," *Clinics in Geriatric Medicine*, L.Z. Rubenstein, L.J. Campbell, and R.L. Kane (eds.) (Philadelphia, PA: W.B. Saunders Co., 1987).

tia. Of the three kinds of inpatient geriatric specialty units, subacute geriatric assessment units probably serve the most patients with dementia. Some of these units do not serve people with severe dementia, however (394).

Inpatient geriatric consultation teams can visit elderly patients on acute medical, surgical, and psychiatric wards throughout a hospital and so have the potential to reach large numbers of hospitalized patients who may have dementia. As consultants, however, the team can evaluate only those patients referred to them by a patient's primary physician (328,723,914). In some cases, differences of opinion about what type of patient will benefit from geriatric assessment or "turf" issues may prevent some patients, including those suspected of having dementia, from receiving an assessment (914).

Information from several sources indicates that many of the clients of *outpatient geriatric services* are elderly people with dementia (272,493,909).

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About one-third of the 1,373 elderly people who received assessments from New Jersey's eight geriatric assessment centers from January 1987 to June 1989 had a diagnosis of Alzheimer's disease or a related disorder (272). Likewise, one-third of the 131 elderly people who received assessments from May 1983 to April 1984 at the Geriatric Ambulatory Consultation Service in Rochester, New York, had a dementing disease (909) (see box 8-L).

Elderly people with dementia also constitute a significant proportion of the clients of many inpatient and outpatient *geropsychiatry services* (12, 493,705). The Geriatric and Family Services Clinic in Seattle, Washington (described in box 8-M) generally evaluates about 250 elderly people with dementia a year (706).

Linking Functions

Information and Referral

The primary functions of all hospital-based geriatric assessment programs are to provide elderly people with a comprehensive multidimensional assessment and to develop an appropriate plan of care. When discussing a patient's plan of care with the patient and his or her family or other informal caregiver, the staff of geriatric assessment programs usually provide information about community services and referrals to specific service providers. In some cases, this occurs only once, however, immediately following the patient's assessment. The referrals provided by many inpatient geriatric assessment programs pertain primarily to a patient's medical needs (723), and some inpatient geriatric assessment programs refer their patients to other information and referral sources in the community for referrals to social and other nonmedical services (724). In contrast, most outpatient geriatric assessment programs provide their patients with referrals to a range of medical and nonmedical services (703, 909).

Although all hospital-based geriatric assessment programs provide their patients with information and referrals to at least some types of community services, most programs are unequipped to provide the general public with information and referrals to community services. Although no definitive data are available, information from several sources suggests that many geriatric assessment programs do not maintain a comprehensive list of community resources for use in referrals (379,699,724).

Case Management

Case management includes five core functions: assessing a client's needs, developing a plan of care, arranging and coordinating services, monitoring and evaluating the services delivered, and reassessing the client's situation as the need arises. The extent to which hospital-based geriatric assessment programs perform functions that go beyond assessing a client's needs and developing a plan of care varies.

One commentator has noted that many inpatient geriatric assessment programs have limited knowledge about nonmedical community services and do not emphasize coordinating such services for their patients or providing followup (746). Outpatient geriatric assessment programs tend to have a closer working relationship with community service providers and are more likely than inpatient programs to arrange and coordinate community services for their patients and to provide followup (493,549,722,907). Some outpatient geriatric assessment programs provide only limited followup after patients are initially linked to services, however (907).

Participants in the 1987 Geriatric Assessment Consensus Development Conference sponsored by the National Institutes of Health agreed that successful implementation of a comprehensive plan of care for an elderly person depends on the availability of case management to link the person to needed services (848). Many participants in the conference recommended that geriatric assessment programs place more emphasis on providing case management. Likewise, some commentators have recommended that all geriatric assessment programs should take a more active role in coordinating social and other nonmedical services for their patients (108,722,907).

Public Education

Some hospital-based geriatric assessment programs distribute brochures and sponsor meetings and other community forums to inform the public about their services (272). Geriatric assessment programs generally do not provide public education about dementia or about services other than their own for people with dementia. Frequently, however, members of geriatric assessment teams give speeches or publish articles that explain the potential value of comprehensive geriatric assessment in accurately diagnosing a patient's medical and psychiatric condition and in developing an appropriate plan of care.

Outreach

Hospital-based geriatric assessment programs do not routinely engage in outreach to identify potential clients (724). Typically, they deal only with patients who are referred to them. The programs sometimes serve patients without families who are referred by a physician, another hospital staff member, or a community agency such as Adult Protective Services.

Role in Allocating Services and Funding

Hospital-based geriatric assessment programs do not control access to, or funding for, services other than those they provide.

Summary

As agencies that might be designated to constitute a national system to link people with dementia to services, hospital-based geriatric assessment programs offer the following advantages:

- Hospital-based geriatric assessment programs provide elderly people with a comprehensive multidimensional assessment that may reveal a treatable cause for their dementia or other treatable diseases and conditions that are exacerbating their dementia and reducing their functional ability.
- Hospital-based geriatric assessment programs provide elderly people with a comprehensive multidimensional assessment that may help match individuals with appropriate services.
- Hospital-based geriatric assessment programs typically have staff who are knowledgeable about dementia.

Despite these advantages, designating hospital-based geriatric assessment programs as the basis of a national system to link people with dementia to services would have several drawbacks. One drawback is that hospital-based geriatric assessment programs generally are not equipped to provide information and referrals to the general public. To do so would require a major redirection of their efforts and resources. A second drawback is that hospital-based geriatric assessment programs generally do not provide outreach to identify people with dementia who would benefit from their services but are unlikely to contact a geriatric assessment program on their own or be referred to the program. A third drawback is that although some hospital-based geriatric assessment programs link their patients to all kinds of community services, inpatient geriatric assessment programs, in particular, often refer their patients primarily to medical services and do not emphasize referrals to or coordination of social and other nonmedical services.

There are several other possible drawbacks to designating hospital-based geriatric assessment programs as the basis of a national system to link people with dementia to services. One of these is that some hospital-based geriatric assessment programs focus primarily on the needs of patients and pay less attention to the needs of family caregivers. Another is that geriatric assessment programs are intended to serve people who want or are willing to accept a comprehensive assessment by a multidisciplinary team; by design, therefore, they may exclude people who do not want or are unwilling to accept a comprehensive assessment. It is unclear how many, if any, people with dementia or their caregivers would be unwilling to accept such an assessment.

Lastly, hospital-based geriatric assessment programs are more expensive than some of the other categories of agencies discussed in this chapter. On the other hand, to the extent that hospital-based geriatric assessment programs can identify and treat diseases and conditions that exacerbate patients' dementia and thus help them to function more independently, these programs can decrease the patients' service needs and thus reduce the overall cost of their care to all payers.

Whether the association of geriatric assessment programs with hospitals is primarily an advantage or a drawback to designating such programs as the basis of a national linking system for people with dementia is unclear. Certainly, many people are comfortable with hospitals as settings for medical care. On the other hand, the patient assessment and care planning provided by hospital-based geriatric assessment programs, particularly inpatient programs, sometimes focuses too greatly on the medical aspects of a person's condition and on referrals to medical services to the exclusion of nonmedical problems and referrals to social and other supportive services.

If hospital-based geriatric assessment programs were designated as the basis of a national system to link people with dementia to services, the programs would have to place more emphasis on coordinating a range of services for their patients. Since outpatient programs tend to do this and are also less expensive than inpatient programs, outpatient programs would generally be more appropriate than inpatient programs as settings for a national linking system. Clearly, however, inpatient programs would be needed for some people with dementia.

HOME HEALTH AGENCIES

Home health agencies are local organizations that provide in-home health care and health-related services that may include any of the following:

- skilled nursing services;
- physical, occupational, and speech therapy;
- social work services;
- homemaker, home health aide, companion, and chore services;
- respite care;
- nutritional services; and
- in-home hospice care.

Some people use the term "home health agency" narrowly to include only agencies that provide the more medically oriented in-home services (e.g., skilled nursing services and physical therapy). As used in this report, however, the term refers to agencies that provide any of the in-home services listed above. According to the National Association for Home Care, in 1989, there were about 12,800 home health agencies in the United States—a figure that includes both Medicare-certified home health agencies and other agencies that provide in-home services but are not Medicare-certified (337).

OTA is including home health agencies in its analysis of agencies that might constitute a national system to link people with dementia to services for several reasons. First, case management is an integral component of the care provided by home health agencies for many of their clients. Second, at least two States, Illinois and New York, are using home health agencies to provide case management for a State-funded, long-term care program. Third, home health agencies are a major player in the delivery of health care and long-term care services in this country. Lastly, home health agencies provide many of the services that may be needed for a person with dementia.

Overview of the Agencies

Home health agencies include many different types of public and private organizations. The public organizations typically are units of State, county, or other local government departments of health or public health. The private organizations include both for-profit and nonprofit agencies. Some home health agencies are independent entities; some are operated by another organization, such as a hospital; and some are part of a multiagency chain (224,773).

Some home health agencies of each of the above-mentioned types are Medicare-certified: that is, they meet the Federal requirements for participation in the Medicare program, including a requirement that they provide skilled nursing services. As of April 1989, 5,681 home health agencies were Medicare-certified (337). Other home health agencies of each of the above-mentioned types are not Medicare-certified, either because they do not meet the requirements for participation in the Medicare program or because they choose not to participate in the program. No precise data are available on the number of home health agencies that are not Medicare-certified, but the National Association for Home Care has estimated that in 1989, more than 7,100 home health agencies (55 percent of all home health agencies) were not Medicare-certified (337). Only Medicare-certified home health agencies can receive Medicare reimbursement for home health services.

The Federal Government collects many different kinds of information in connection with the certification of home health agencies for Medicare and the payment of Medicare home health claims. Thus, as illustrated in the following discussion, much more is known about Medicare-certified home health agencies than about non-Medicare-certified home health agencies (224,340).

The proportion of home health agencies that are Medicare-certified varies among States. In 1987, for example, 85 percent of the 194 home health agencies in Arkansas were Medicare-certified, compared to only 21 percent of the 821 home health agencies in New York (340,570).

Table 8-2—Services Provided by Medicare-certified Home Health Agencies, 1986, N = 5922

Service	Percentage of agencies that provide the service	Percentage of agencies that provide the service using agency staff
Nursing services	100%	99 %
Home health aide or homemaker	97	88
Physical therapy	89	53
Speech therapy	74	37
Medical social work services	61	45
Occupational therapy	59	32
Nutritional guidance	28	21
Medical appliances or equipment	21	9
Pharmaceutical services	10	5
Physicians' services	1	0.8

SOURCES: Foundation for Hospice and Home Care, *Basic Home Care Statistics: The Industry 1988*, Washington DC, 1988; S.L. Hughes, Center for Health Services and Policy Research, Northwestern University, Evanston, Illinois, "Home Care: Where We Are and Where We Need To Go," draft prepared for the National Institute on Aging In-Home Community and Supportive Services Advisory Group, Bethesda, MD, Apr. 19, 1990.

As of April 1989, 18 percent of the Medicare-certified home health agencies were public agencies; 32 percent were private, for-profit agencies; 13 percent were private, nonprofit agencies; 9 percent were visiting nurse associations (VNAs); 26 percent were hospital-based agencies; and the remaining 2 percent were nursing home or rehabilitation-based agencies or agencies under combined auspices (337). No similar information is available about non-Medicare-certified home health agencies.

Medicare-certified home health agencies are permitted to provide in-home services directly—i.e., using the agency's staff, or through contracts with other providers. Data on the services provided by Medicare-certified home health agencies in 1986 show that all or the great majority of these agencies were providing nursing, home health aide, and homemaker services and were using agency staff to provide these services (see table 8-2). Fewer agencies were providing other types of in-home services, and the agencies that were providing the other types of services were more likely to be using contractors to provide them (224,340). No similar data are available on the services provided by non-Medicare-certified home health agencies.

Home health agencies generally employ registered nurses, licensed practical nurses, home health aides, homemakers, and social workers (224). Some home health agencies also employ physical therapists, speech therapists, occupational therapists, and a variety of other service providers, whereas other home health agencies contract with these types of service providers (224,822). A 1987 analysis of the employment patterns in Medicare-certified home health agencies indicates that the average home health agency employed 7 registered nurses and 5 home health aides (337). Again, no similar figures are available for non-Medicare-certified home health agencies.

Home health agencies are licensed by some States and territories, but not by others. OTA's tabulation of the results of a survey by the National Association for Home Care (571) shows that, as of March 1989, 35 States and territories licensed Medicare-certified home health agencies, and 30 States and territories licensed non-Medicare-certified home health agencies.

The number of home health agencies increased greatly in the past 25 years, from an estimated 1,200 agencies in 1965 to more than 12,800 in 1989 (224,337). The number of Medicare-certified home health agencies increased from 1,753 in 1967 (the second year in which there was Medicare certification for home health agencies) to more than 6,000 in 1986, and then decreased to 5,681 by April 1989 (224,337,773). OTA is not aware of any data on the number of non-Medicare-certified agencies in the late 1960s, but recent estimates suggest that in the past few years, the number of non-Medicare-certified agencies continued to increase, even though the number of Medicare-certified agencies dropped somewhat.

The predominant types of home health agencies also changed over time. In 1967, 37 percent of all Medicare-certified home health agencies were VNAs, and 54 percent were public agencies (224). By 1972, a smaller percentage of Medicare-certified home health agencies (24 percent) were VNAs, but public agencies still constituted more than half (57 percent) of all such agencies (773). By 1989, however, only 9 percent of all Medicare-certified home health agencies were VNAs, and only 18 percent were public agencies (337).

As the proportion of VNAs and public agencies decreased, the proportion of other types of home health agencies increased. During the 1970s, private, nonprofit agencies were the fastest growing type of Medicare-certified home health agency, increasing from less than 1 percent of all such agencies in 1972 to 14 percent in 1982 (773). From 1982 to 1986, private, for-profit home health agencies were the fastest growing type of Medicare-certified home health agency, increasing from 17 percent of all Medicare-certified home health agencies in 1982 to 32 percent of all such agencies in 1986 (453,773)[19]. For the past few years, hospital-based home health agencies have been increasing faster than any other type of Medicare-certified home health agency (453,773).[20]

No information is available about the proportion of various types of home health agencies among non-Medicare-certified agencies, but the National Association for Home Care believes that for-profit agencies that serve only private pay clients are increasing (224). Durable medical equipment supply agencies, which are not usually classified as home health agencies even though they provide in-home medical therapies (e.g., mechanical ventilation, IV antibiotics, and chemotherapy) are also increasing (773).

In-home services are paid for by Medicare, Medicaid, other Federal, State, and local government health care and long-term care programs, patients, patients' families, charitable organizations, and other sources (469,811,821). Many private insurers pay for in-home services, and at least 17 States require private insurers to include home health benefits in their plans (773). As of May 1989, 73 of the 90 Blue Cross and Blue Shield plans offered home health benefits (401).

Medicare is the largest third-party payer for home health care. As noted earlier, Medicare pays only for in-home services that are provided or contracted for by Medicare-certified home health agencies. Medicare expenditures for in-home services for 1989 were estimated to be $2.9 billion (3 percent of total Medicare expenditures) (337,837). Data for fiscal year 1984 show that Medicare payments accounted for almost three-quarters of the revenues of Medicare-certified home health agencies in that year (224), but anecdotal evidence suggests that proportion may have decreased since then.

Non-Medicare certified home health agencies receive funds from all the sources listed above, except Medicare. OTA is not aware of any information about the proportion of funds from various sources that are received by non-Medicare-certified home health agencies. Nor is OTA aware of any information about the proportion of funds from sources other than Medicare that are received by Medicare-certified home health agencies.

Medicaid expenditures for in-home services amounted to nearly $1.4 billion in 1986 (224). It should be noted, however, that Medicaid and all sources of funding for in-home services other than Medicare pay for services that are provided not only by Medicare-certified and non-Medicare-certified home health agencies, but also by individual providers who are not connected with a home health agency (298,821). Thus, expenditures for in-home services by sources other than Medicare are not necessarily payments to home health agencies.

Who Is Served

The question of who is served by home health agencies is particularly important in considering the capacity of home health agencies to link people with dementia to services because, as discussed later in this section, the case management that is provided by home health agencies generally is "service-centered"—i.e., it is usually provided only for people who are receiving other services from the agencies.

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[19] Before 1981, for-profit home health agencies could not be Medicare-certified in States that did not have licensure laws for such agencies. The Omnibus Budget Reconciliation Act of 1980 (Public Law 96-499) (effective July 1981) allowed those agencies to participate in the Medicare program, thereby spurring a dramatic increase in the number and percentage of Medicare-certified private, for-profit agencies.

[20] The recent increase in hospital-based home health agencies reflects, in large part, the attempt by hospitals to expand their services in other areas to compensate for decreases in the use of inpatient care following the implementation of the Medicare Prospective Payment System in 1983, and of other similar government and nongovernment initiatives that have been implemented in the past few years to control the use and cost of inpatient hospital care (453,773)

Virtually all the available information about who is served by home health agencies pertains to individuals who receive Medicare-funded services from Medicare-certified home health agencies. In 1986, 1.6 million individuals received Medicare-funded services from such agencies; 94 percent of the individuals were over age 65, and 64 percent were women (733). The 10 most frequent diagnoses for these 1.6 million individuals were: cerebrovascular disease, congestive heart failure, hip fracture, chronic airway obstruction, hypertension, diabetes, pneumonia, other pulmonary conditions, heart attack, and urinary incontinence.

These diagnoses accounted for only one-fourth of the individuals. Medicare enrollees over age 85 were 4 times more likely than Medicare enrollees age 65 or 66 to receive Medicare-funded in-home services.

It has been estimated that people who receive Medicare-funded in-home services constitute 60 to 100 percent of the clients of individual Medicare-certified home health agencies (538). If that estimate is correct, then up to 40 percent of the clients of some Medicare-certified home health agencies receive in-home services that are not Medicare-funded. Very little information is available about those people or about people who receive in-home services from non-Medicare-certified home health agencies.

The 1982 National Long-Term Care Survey—a large-scale study of a nationally representative sample of elderly people who had at least one limitation in activities of daily living (ADLs) or instrumental activities of daily living (IADLs)—gathered information on the subjects' use of in-home services. Data from the survey show that only 26 percent of the subjects received any paid in-home services, including 20 percent who received both paid and unpaid (informal) in-home services and 6 percent who received only paid in-home services (469).

The extent to which the paid in-home services received by subjects of the 1982 National Long-Term Care Survey were provided by home health agencies is unclear. Among the subjects who received any paid in-home services, 14 percent received services that were paid for by Medicare (469); these services were undoubtedly provided by Medicare-certified home health agencies. Seven percent of the survey subjects received in-home services that were paid for in whole or in part by Medicaid; 2 percent received services paid for in whole or in part by private insurance, and more than 40 percent received in-home services they paid for themselves. The in-home services paid for by Medicaid, private insurance, and individuals for themselves may or may not have been provided by home health agencies. Evidence from various sources suggests that families and other informal caregivers of people with dementia who use paid in-home services often hire maids, sitters, and other individuals who are not employed by or under contract to a home health agency to provide the services (291,934).

Although little comprehensive information is available about people who are served by home health agencies, much has been written about factors that influence who is served by these agencies. Probably the major factor that influences who is served by home health agencies is the availability of reimbursement—particularly reimbursement from Medicare. The Medicare home health services benefit is medical in orientation, and eligibility for the benefit is restricted to "homebound" individuals who need part-time or "intermittent" skilled nursing services and/or physical therapy or speech therapy. A physician must certify that one of these three services is "medically necessary" for an individual. Medicare also pays for home health aide services, occupational therapy, and social work services, but only for individuals who are eligible for Medicare-funded skilled nursing services, physical therapy, or speech therapy.

Like the Medicare home health services benefit, private insurance benefits for in-home services generally are medically oriented,[21] as are the in-home services that States are required to provide in their Medicaid programs. The Federal Medicaid program also gives States the option to provide health-related personal care services, but funding for these less medically oriented in-home services and for similar in-home services paid for with Older Americans Act and Social Services Block Grant funds is significantly less than the funding for the medically oriented services paid for by Medicare, private insurance, and the required Medicaid program. Thus, there are strong financial incentives for home health agencies to serve people who need medically oriented in-home services.

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[21] Blue Cross and Blue Shield coverage extends, much as Medicare's coverage does, only to home care that has been certified by a physician as being medically necessary. The company's "long-term care benefit," which permits the provision of nonmedical "custodial" (or supportive) care, is currently being marketed by only 15 of the 73 plans (401).

Another factor that influences who is served by home health agencies is technological advances that allow the provision at home of sophisticated medical treatments, such as mechanical ventilation, IV antibiotics, and chemotherapy, previously available only in hospitals (340,821,830). To the extent that reimbursement is available for the use of these treatments at home, there is an incentive for home health agencies to serve people who need those treatments.

A third factor that influences who is served by home health agencies is the Medicare Prospective Payment System and other government and nongovernment programs that have created financial incentives for shorter hospital stays. As a result of these programs, more people are discharged from hospitals in a medically unstable condition and are in need of short-term, post-hospital acute care. Since the needs of these individuals generally correspond to the eligibility criteria for Medicare-funded in-home services, there are financial incentives for home health agencies to serve them.

When the Prospective Payment System was implemented in 1983, many analysts suggested that there would be a large increase in the number of people who received Medicare-funded in-home services (449,822). That increase did not materialize. In fact, the annual rate of increase in the number of people who received Medicare-funded in-home services for the years 1983-86 was smaller than it had been for the preceding 4 years (1980-83) (733). Instead, there was an increase in Medicare denials of reimbursement for in-home services (449,836). These denials generally were explained on the grounds that the in-home services had been provided for individuals who were not "homebound," that the services were not "medically necessary" or "intermittent," or that they did not constitute "skilled nursing care" as defined in the Medicare regulations. Anecdotal evidence suggests that the impact of the denials has been to push Medicare-certified home health agencies further in the direction of serving individuals who need medically oriented in-home services, particularly short-term, post-hospital acute care services, and individuals who are so severely impaired that they cannot leave their homes. This effect has been exacerbated by the growth in the overall number of home health agencies, the resulting competition among agencies for limited funds, and cuts in Federal funding for programs that pay for nonmedical in-home services (776,922).

Some researchers who have studied the changes in the home care field in recent years have noted a shift in the field "from providing services to a concern with providing *profitable* services" (922). They comment:

> The national focus on cost containment . . . has increased the competition not only between proprietary [for-profit] and nonprofit agencies, but also among nonprofit agencies themselves. It is an interesting dilemma for nonprofit agencies that have operated on an ideology of providing services as opposed to competing in an economic marketplace and especially for those that do not offer clearly defined medical services. Agencies that provide supportive services have been faced not only with the need to become more competitive in general but also to alter their service structure to at least appear as if they are quasi-medical. This is necessary if they are to either recapture some of their lost government funding or become more competitive in the open market (922).

Some people who work in home health agencies and are knowledgeable about the changes that have occurred in the home health care field in recent years have told OTA that although they recognize the importance of medically oriented in-home services and short-term, post-hospital acute care services, they regret the shift away from the public health or community health model of home care that was the norm when VNAs and government agencies were the predominant types of home health agencies. That model of home health care, which may be best characterized as a nursing rather than a medical model, focuses on the family, not just the individual patient, and stresses preventive health services, health education, coordination of services, and long-term, supportive services for people with chronic conditions (42). Although many VNAs, government agencies, and to a lesser degree, other types of home health agencies continue to provide these types of services and to serve individuals who need these types of services, it is probably becoming increasingly difficult for them to do so because of the pressures discussed earlier.

The extent to which home health agencies serve people with dementia is unclear. The preceding discussion of factors that influence who is served by home health agencies suggests several reasons why home health agencies might not be serving many people with dementia. In addition, family caregivers and advocates for people with dementia often complain that the eligibility requirements for Medicare-funded in-home services discriminate against people with dementia and that the medically oriented services provided by many home health agencies are not appropriate for the needs of people with dementia. Data from the 1982 National Long-Term Care Survey indicate that survey subjects who were said to be "senile" by the proxy respondents who answered the survey questions for them and survey subjects who had characteristics that suggested they might have dementia (e.g., they needed help in taking medicines), were more likely than other survey subjects to have unmet needs for in-home services and to be paying for their own in-home services (469,811).

On the other hand, OTA's informal discussions with individuals who work for home health agencies suggest that these agencies are serving many people with dementia. Individuals who work for home health agencies often express frustration about the lack of adequate funding for in-home services for people with dementia and concern about the difficulty of providing in-home services for dementia patients who frequently are not aware of their need for services and may not be capable of making decisions about services for themselves. It is clear, however, that many of their clients are people with dementia.

Two analyses of data from the 1982 National Long-Term Care Survey and 1982 Medicare billing records—one by the General Accounting Office and the other by researchers at Duke University—shed some light on the question of whether home health agencies serve people with dementia (490a,811). Both analyses were intended to identify distinct categories of individuals who receive Medicare-funded in-home services. Both research groups identified a category of individuals who are chronically ill, have multiple medical problems, including diseases and conditions that cause dementia, and are severely functionally impaired. Moreover, both research groups found that, on average, individuals in this category received more Medicare-funded in-home services than individuals in any of the other identified categories, including the categories of individuals with severe medical problems such as hip fractures, cancer, and heart attack. The Duke University research group also identified another category of individuals who had cognitive impairments, but few acute or severe medical problems. On average, individuals in the latter category received fewer Medicare-funded in-home services than individuals in any of the other categories. These findings suggest that at least with respect to Medicare-certified agencies, people with dementia who have medical problems in addition to their cognitive impairments are likely to be served, whereas people with dementia who do not have other medical problems may be less likely to be served by the agencies.

In addition to their regular services, some home health agencies have established special programs for people with Alzheimer's and other diseases that cause dementia. Box 8-N describes AL-C*A*R*E*, a joint project of two home health agencies in Washington, DC, that provides in-home respite care and other services for people with dementia and their caregivers. The project is funded primarily by the DC Office on Aging.

Another home health agency that has established a special program for people with dementia is the Visiting Nurse Association of the Valley, a Medicare-certified VNA in Derby, Connecticut (341). The program provides in-home mental health services for people with dementia and their caregivers and for elderly people with medical conditions whose progress is impeded due to psychological problems. Originally established in 1979 with a Federal grant, the program now receives both State funds and some Federal grant funds.

Both AL-C*A*R*E* and the program of the Visiting Nurse Association of the Valley provide special training for the homemakers and home health aides who work for the agencies' dementia programs. Apart from the staff of special Alzheimer's programs, though, it is unclear to what extent the staff of home health agencies are knowledgeable about dementia. In the course of this study, OTA staff heard many complaints about home health agency staff members who were said to be uninformed about dementia and the care of people with dementia. No data are available to determine the extent of this problem.

*Box 8-N—AL-C*A*R*E*: A Dementia-Specific Project of Two Home Health Agencies in Washington, DC*

AL-C*A*R*E* (Alzheimer's-Coordination, Assessment, Respite, Education) is a joint project of the Visiting Nurse Association of Washington, a Medicare-certified home health agency, and Homemaker Health Aide Services of the National Capital Area, a homemaker-home health aide agency that is not Medicare-certified. AL-C*A*R*E* serves residents of Washington, DC, who are over age 60, live with a caregiver, and have a dementing illness severe enough to interfere with their daily functioning. The project provides in-home assessments, information and referral, respite care, and caregiver training and support.

AL-C*A*R*E's in-home assessments are done by a nurse practitioner employed by the Visiting Nurse Association of Washington and a social worker employed by Homemaker Health Aide Services of the National Capital Area. Since the primary objective of the project is to support caregivers, the in-home assessments focus as much on the needs of the primary caregiver as on the needs of the patient. Reassessments are conducted every 3 months. The social worker furnishes referrals to other community service providers, as needed, and the nurse practitioner provides a link to the patient's physician.

AL-C*A*R*E*'s in-home respite services are provided by specially trained homemakers who are employed by Homemaker Health Aide Services of the National Capital Area and have volunteered to work in the AL-C*A*R*E* project. The specific in-home services provided by the homemakers differ depending on the needs of the patient and caregiver. Less emphasis is placed on the completion of home management tasks than on furnishing whatever assistance will offer relief to the caregiver. Whenever possible, respite services are provided at times selected by the caregiver. As of June 1988, there was no charge for the respite services, but a contribution of $2 an hour was suggested.

The AL-C*A*R*E* homemakers receive an 8-hour orientation that includes information about Alzheimer's and other diseases that cause dementia and the impact of the diseases on patients and their families and suggestions about caregiving techniques and methods for supporting and assisting caregivers. The homemakers are supervised on an ongoing basis by the project social worker who assists the homemakers in problem-solving and provides emotional support for them. Bimonthly meetings are held for the homemakers to provide additional information about caregiving techniques, and to give the homemakers an opportunity to share feelings about their work in a supportive atmosphere.

One of AL-C*A*R*E*'s major objectives is to provide information and education for caregivers. Caregivers are given a "Family Information Packet" that was developed by AL-C*A*R*E* and contains an overview of Alzheimer's disease; tips on caring for and communicating with people with dementia; suggestions for dealing with problems, such as wandering and incontinence; lists of local support groups, sources of legal services and adult day centers; an "environmental check list" of common safety problems in the home; and a list of publications about dementia. The nurse practitioner provides caregiver education and training about common health problems in people with dementia, medications, nutrition, approaches for handling problem behaviors, and stress reduction techniques for the caregivers. Caregiver training groups are held about eight times a year. Sometimes guest speakers are invited to discuss issues of special interest to caregivers, but the training groups also provide emotional support for caregivers.

SOURCES: M.Z. Kocin, project director, AL-C*A*R*E*, Washington, DC, personal communication, June 21, 1988; M.Z. Kocin and V. Kendrick, "AL- C*A*R*E*: A Respite Model for Long-Term Care," *Caring* 7(4):39-43, April 1988.

In 1986, the Foundation for Hospice and Home Care published a training manual, *How To Care for the Alzheimer's Disease Patient: A Comprehensive Training Manual for Homemaker-Home Health Aides* (378), and other relevant training materials have also been developed (see, e.g., E.L. Ballard and L.P. Gwyther, *In-Home Respite Care: Guidelines for Training Respite Workers Serving Memory-Impaired Adults* (50)). OTA does not know how widely these training materials are used or what, if any, special training about dementia is available to the staff of home health agencies.

Linking Functions

Information and Referral

The primary function of home health agencies is to provide in-home services for their clients. People who are already receiving in-home services from a home health agency and need services that are not offered by the home health agency (e.g., home-delivered meals or legal services) are often

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referred to other agencies for the needed services. These referrals are usually made by a home health agency nurse or by a home health agency social worker if the client is being seen by a social worker. Anecdotal evidence indicates that other home health agency staff members, including homemakers and home health aides, also sometimes refer agency clients to other community service providers.

Home health agencies generally are not in the business of providing information and referrals for the general public. Nevertheless, people who call a home health agency for services often receive a referral to another community agency or individual service provider if the home health agency does not offer the services they need or if they are not eligible for the home health agency's services. An intake nurse at one home health agency estimates, for example, that she refers an average of one-third of all incoming calls to other agencies or individual service providers (239). OTA is not aware of home health agencies that have followup procedures to determine whether individuals who receive such referrals but are not clients of the agency obtain the services they need.

Home health agencies typically do not develop and maintain comprehensive community resource lists for use in referring their clients and other callers to services (239). Instead, some home health agency nurses and other staff members use resource lists developed by other agencies, and some make referrals on the basis of their own knowledge of agencies and individual service providers in the area. One commentator has suggested that home health agency nurses and other staff members are probably more likely to have the names of community service providers "on their roladex" than to use a comprehensive resource list (239).

Case Management

Unlike providing information and referrals, case management is a primary function of home health agencies. The home care industry points out that home health agencies "have been acting as case managers for many years, providing those services they can and trying to arrange for other services the patient may need through other community service agencies" (275). Certainly, the five functions that OTA has defined as core case management functions (i.e., assessing a client's needs, developing a plan of care, arranging and coordinating services, monitoring the services, and reassessing the client's situation) have always been part of community health nursing and public health nursing (22,265) and are integral components of the community health or public health model of home care.

Photo credit: On Lok Senior Health Services

The case management provided by home health agencies generally is service-centered; that is, it is provided for people who are receiving in-home services from the agencies.

The extent to which case management functions are provided by different types of home health agencies and for different types of clients undoubtedly varies, but the results of a 1987 study of home visits by nurses from Medicare-certified home health agencies in five States show that, on average, case management functions constituted almost half of the total nursing time associated with the visits (776). The researcher observed 75 home visits by 26 nurses from 8 home health agencies—one VNA, one public agency, 2 private, for-profit agencies, and 4 hospital-based agencies. The study found that the average nursing time associated with a home visit (not counting travel time) was 73 minutes, of which 41 minutes were spent in the client's home, and 32 minutes were spent before or after the visit on care coordination functions, such as contacting other service providers for the client and documentation. On average, 20 percent of the total nursing time associated with a home visit was spent on client assessment, and 26 percent was spent on care coordination. Psychosocial support, which also might be considered case management, accounted for an additional 9 percent of total nursing home associated with the typical visit. Other components of the visit were client education, which accounted for 13 percent of the nursing time associated with the typical visit, documentation, which accounted for 19 percent, and physical care, which accounted for 9 percent. Although the small number of home health agencies studied means that the results of the study cannot be generalized with any certainty, its findings tend to support the conclusion that home health agencies are providing case management.

Twenty percent of the 75 home visits observed by the researcher were initial visits to the client, and 80 percent were repeat visits (776). In general, more time was spent on assessment and care coordination in the initial visits than the repeat visits. There were also differences in the average amount of time spent on different functions by nurses from different types of home health agencies. Nurses from the VNA and the public agency spent more time than nurses from the private, for-profit and hospital-based agencies on physical care and care coordination, whereas nurses from hospital-based agencies spent more time on assessment. The important finding of the study for this OTA assessment is not any of the precise percentages or specific differences between types of home health agencies, however, but the large proportion of total nursing time devoted to case management functions.

As noted earlier, the case management provided by home health agencies generally is service-centered; that is, it is furnished in conjunction with the provision of services. Thus, people who receive services from a home health agency may also receive case management, but people who are not receiving services from the agencies are unlikely to receive case management. Some people favor service-centered case management because they think that case management is performed most effectively in conjunction with the provision of services and that patients and families are often more comfortable with case management performed by a service provider, such as a home health nurse, than by someone whose sole function is case management (283,290). Other people are opposed to service-centered case management because they think that service providers tend to over-recommend services and to refer their clients to the agencies' own services even when other, more appropriate services may be available from another agency. These differing contentions are discussed in chapter 1. With respect to home health agencies' capacity to link people with dementia to services, the important point is that people with dementia may need case management at any time in the course of their illness, not just at those times when they need the kinds of services provided by home health agencies.

Both Illinois and New York use home health agencies to provide case management for a State-funded long-term care program, and in both States, the home health agencies provide case management for some people who are not receiving in-home services from the agency. In Illinois, one-third of the agencies that furnish case management for the State's Community Care Program are home health agencies. These home health agencies are not permitted to provide in-home services for the program's clients (587). In New York, as of 1986, 46 percent of the 95 local agencies providing case management for the State's Nursing Home Without Walls Program were home health agencies (472). These agencies have the option to provide services for the program's clients but do not always do so (354).[22]

In general, the case management provided by home health agencies is paid for only indirectly, if at all, by third-party payors. For many programs that pay for in-home services, some of the costs of case management are included in the reimbursable administrative costs associated with the provision of in-home services. The case management provided by home health agencies in the Illinois and New York programs just described is paid for by Medicaid.

Visiting Nurse and Home Care, Inc., a VNA in Hartford, CT, operates an Alzheimer's Disease Program that provides case management for people with dementia (see box 8-O). Some of the in-home services that the program provides or arranges for its clients are paid for by Medicare. Other services are paid for by Medicaid, private insurance, patients and their families, United Way, or State grant funds. In addition, each of the nine towns served by Visiting Nurse and Home Care, Inc. has a contract with the agency to provide services for its residents who have no other source of funds for needed services (283). The case management provided by the Alzheimer's Disease Program is paid for, generally indirectly, with funds from all these sources.

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[22] Illinois' Community Care Program and New York's Nursing Home Without Walls Program are discussed in ch. 7.

Public Education

Home health agencies perform some public education activities. Home health agency nurses sometimes conduct educational programs at senior centers, adult day centers, nursing homes, and congregate living facilities. Such programs often focus on topics such as nutrition, diabetes, and high blood pressure (239). The programs—while increasing the agency's visibility—also provide a valuable service to the public. In addition, home health agency staff members sometimes distribute pamphlets and other educational materials to their clients. OTA does not know how frequently these programs and educational materials focus on Alzheimer's disease, dementia, or services for people with dementia.

Outreach

Many home health agencies perform various outreach activities. Frequently, a home health agency nurse who is visiting a client in an apartment building or a congregate living facility identifies other people in need of care. The nurse may inform the manager of the facility of the home health agency's services and leave the agency's number. Sometimes, one client of a home health agency informs the agency nurse that another individual needs assistance (239). Home health agency nurses may also be involved in community screening programs and identify people in need of services through such programs. As a result of these activities, home health agencies undoubtedly reach some people with dementia and some caregivers who need help but would not seek services themselves. On the other hand, home health agencies generally do not have systematic procedures for identifying isolated people with dementia and isolated caregivers. In fact, some home health agency staff members would probably consider the implementation of such procedures inappropriate at present because of the insufficient availability of in-home services and funding for in-home services for people with dementia.

Role in Allocating Services and Funding

Most home health agencies do not control access to services other than those they provide. On the other hand, home health agencies provide services funded by many different programs. Consequently, they are frequently required to determine who will receive services and what services they will receive within the context of the eligibility and coverage regulations of the funding programs. In addition, as noted earlier, at least two States, Illinois and New York, use home health agencies to provide case management in a State-funded long-term care program, and the functions of the agencies that provide case management in these programs include determining people's eligibility for services and allocating services and funding for services. Other States and local governments may also use home health agencies in this capacity.

Summary

As agencies that might be designated to constitute a national system to link people with dementia to services, home health care agencies offer several advantages:

- Home health agencies serve people of all ages and have extensive experience serving elderly people.
- Home health agencies provide case management for many of their clients.
- Home health agencies provide information and referrals for their clients and for some people who are not their clients.
- Home health agencies often regard family members and other informal caregivers as part of the client unit, and conduct an assessment and develop a plan of care that includes the needs of these caregivers as well as the needs of the patient.
- There are more than 12,000 home health agencies across the country.

Despite these considerable advantages, there would be several drawbacks to designating home health agencies as the basis of a national system to link people with dementia to services. One drawback is that home health agencies generally provide case management only for people who are receiving in-home services from the agency. People with dementia may need case management at any time in the course of their illness, not just at times when they need or are receiving in-home services. This section has discussed many factors that are pushing home health agencies more in the direction of serving people who need medically oriented in-home services—particularly short-term, post-hospital, acute care services. Although some individuals with

Box 8-O—The Alzheimer's Disease Program of Visiting Nurse and Home Care, Inc., in Hartford, Connecticut

Since 1984, the Hartford branch of Visiting Nurse and Home Care, Inc., a Medicare-certified home health agency, has operated an Alzheimer's Disease Program that provides case management and in-home services for people with dementia and their caregivers. Visiting Nurse and Home Care, Inc., serves a nine-town region in the greater Hartford area. As of 1988, the Alzheimer's Disease Program was serving 40 to 50 people at a time. According to the program coordinator, the clients of the Alzheimer's Disease Program are generally retained for longer periods and require more case management than other clients of Visiting Nurse and Home Care, Inc.

The Alzheimer's Disease Program makes use of all the services offered by Visiting Nurse and Home Care, Inc. Consequently, clients of the program have access to all the clinical services of the home health agency, including nursing, physical therapy, speech therapy, occupational therapy, medical social work, home health aide, homemaker, and chore services, and home-delivered meals. In addition, the Alzheimer's Disease Program has developed relationships with local agencies and individuals that provide a variety of services for people with dementia, and there are many cross referrals between the Alzheimer's program and these other service providers.

Initial referrals to the Alzheimer's Disease Program come primarily from families or doctors. Since the Alzheimer's Disease Program started, a monthly average of 25 to 26 people who are referred to Visiting Nurse and Home Care, Inc. have some problem in mental status that is mentioned at the time of the referral. Those individuals are referred to the Alzheimer's Disease Program. In addition, other clients of Visiting Nurse and Home Care, Inc., who are identified as potentially benefiting from the Alzheimer's Disease Program, are also referred to the program. According to the program coordinator, families of people with dementia often contact the program for information about services several times, often over a period of months or years, before actually deciding to use help.

The Alzheimer's Disease Program is staffed by a geriatric services' group consisting of three registered nurses and a social worker. Both a geriatrician and geriatric psychiatrist are available to the program for consultation.

The Alzheimer's Disease Program provides a professionally led support group for the families and other informal caregivers of its clients. A home visit is required before a caregiver is admitted to the support group. To encourage caregivers to attend the support group, the program arranges for sitters for the dementia patients and/or transportation for the caregivers. The support group meets once a week for 10 weeks. Then, the participants can elect to join a monthly ongoing support group. The program coordinator has noted that participants demonstrate significant changes in their caregiving behavior after attending support group meetings: some elect to use respite care for the first time, others seek necessary institutionalization, and others involve their family members more in caring for the patient.

For the personnel who work with dementia clients, the Alzheimer's Disease Program provides regular in-service education and is developing a support group. Another support group has been organized for professionals who work in isolation in the community with dementia patients. A monthly case conference is held for geriatric nurses and other professionals who have an interest in geriatrics and who are used as "backup" staff as the patient load increases.

SOURCE: Visiting Nurse and Home Care, Inc., VNA Health Resources, Inc., and VNA Fund, Inc., "Annual Report," prepared by L. Preble, and M. Cushman, Plainville, CT, 1987; N. Gustafson, program coordinator, Alzheimer's Disease Program, Visiting Nurse and Home Care, Inc., Hartford, CT, letter to the Office of Technology Assessment, U.S. Congress, Washington, DC, Feb. 24, 1988.

dementia need such services, many do not. Individuals who do not need the type of services provided by home health agencies are unlikely to receive those services and therefore unlikely to receive case management from the agencies.

A second drawback is that although home health agencies provide information and referrals for their clients and in connection with intake for their own services, they usually do not consider the provision of information and referrals for the general public as one of their primary functions. Many home health agencies do not maintain a comprehensive resource list to use in referring callers to community service providers, and most do not have systematic follow-up procedures to determine whether people who are not their clients but for whom they provide referrals actually obtain the services.

A third drawback is that home health agencies generally do not have systematic outreach procedures to identify isolated people with dementia and isolated caregivers who are not able to seek help for themselves. Lastly, although home health agencies

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have extensive experience in providing in-home services for elderly people, including some people with dementia, anecdotal evidence suggests that some home health agency staff members are not knowledgeable about dementia or the care of people with dementia.

In considering the capacity of home health agencies to constitute a national system to link people with dementia to services, the large number of home health agencies is an advantage. It is unclear, however, if Congress designated home health agencies to constitute such a system, whether the system should be made up of: 1) all Medicare-certified home health agencies, 2) only certain types of Medicare-certified home health agencies (e.g., Medicare-certified VNAs, public agencies, and private, nonprofit agencies); 3) certain types of home health agencies regardless of their certification status; or 4) all Medicare-certified and non-Medicare-certified home health agencies. Given the existing link between the Federal Government and Medicare-certified home health agencies, it might be easier to implement a national linking system if only Medicare-certified agencies were included. Moreover, the Federal Medicare regulations create a certain uniformity and some basic standards for Medicare-certified agencies. On the other hand, some non-Medicare-certified agencies, particularly some homemaker-home health aide agencies, provide in-home services that closely match the needs of many people with dementia, and these agencies would be valuable components of the linking system. If Congress chose to designate home health agencies to constitute a national linking system, this issue would require further analysis.

SOCIAL HEALTH MAINTENANCE ORGANIZATIONS

A social health maintenance organization (S/HMO) (pronounced shmō) is an innovative organizational entity that offers voluntarily enrolled, elderly Medicare beneficiaries a package of acute and long-term care services and operates on a capitated, prospectively fixed budget. In essence, a S/HMO expands the acute care financing and service delivery model of a health maintenance organization (HMO) to include some long-term care services. As of 1990, there are four S/HMOs in the United States, all of which are part of a congressionally mandated demonstration project—the National S/HMO Demonstration.[23] The four S/HMOs are:

- *Medicare Plus II*, in Portland, Oregon, which is sponsored by a large HMO with more than 280,000 members and extensive experience in providing acute care services to Medicare beneficiaries (Kaiser Permanente);
- *Seniors Plus*, in Minneapolis, Minnesota, which is sponsored by a partnership between a large HMO (Group Health, Inc.) and a long-term care agency (the Ebenezer Society);
- *Elderplan*, in Brooklyn, New York, which is sponsored by a comprehensive long-term care agency with no prior experience in administering a prepaid health plan (Metropolitan Jewish Geriatric Center); and
- *SCAN Health Plan*, in Long Beach, California, which is sponsored by a case management agency with no prior experience in administering a prepaid health plan (Senior Care Action Network) (274,841).

OTA has included S/HMOs in its analysis of agencies that might constitute a national system to link people with dementia to services because, in theory at least, the S/HMO model of service delivery in which a single organization provides or contracts for and arranges acute and long-term care services for its members eliminates for those individuals many of the problems in locating and arranging services that are the topic of this OTA report (421). S/HMOs link some of their members to many of the kinds of services that may be needed for a person with dementia, and it is conceivable that S/HMOs could link all of their members with dementia to such services.

Overview of the Agencies

The National S/HMO Demonstration requires the four S/MHOs to offer their members all the acute health care services that Medicare covers (e.g., hospital inpatient and outpatient services, physician and diagnostic services, and specified home health care and skilled nursing home services) (841). In addition, the S/HMOs are required to offer their members certain other services not covered by Medicare, including long-term care services such as personal care, homemaker services, adult day care, respite care, transportation, and 2 to 4 months of nursing home care beyond the Medicare benefit (274,452).

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[23] The national S/HMO demonstration was mandated by the Deficit Reduction Act of 1984 (Public Law 98-369). It began in 1985, and will continue as a demonstration until September 1992 (2,841).

To meet the requirements of the National S/HMO Demonstration, the HMO that sponsors Medicare Plus II had to add long-term care services to the acute care services it was already offering its elderly members (841). In contrast, the agencies that sponsor Elderplan and SCAN Health Plan had to add the acute care services required by the demonstration to the case management and long-term care services they were already offering—in effect by setting up new HMOs. Having to start new HMOs was a major challenge for these agencies (269,452). Seniors Plus is cosponsored by an HMO and a long-term care agency, and these agencies were already offering, respectively, the required acute care and long-term care services. According to one commentator, the S/HMOs that are sponsored or cosponsored by HMOs (Medicare Plus II and Seniors Plus) had less difficulty than the other two S/HMOs in enrolling members (half of Medicare Plus II's and more than half of Seniors Plus' S/HMO members were conversions from their affiliated HMOs) (295). The S/HMOs sponsored or cosponsored by HMOs also had more previous experience with controlling health care utilization and processing payments within a managed care system (295).

Although there are currently only four S/HMOs in the United States, existing HMOs could provide a basis for developing more S/HMOs. As of May 1987, there were at least 734 HMOs in this country (279), 214 of which had elected to participate in the Medicare program (588,840). Established HMOs that already serve Medicare beneficiaries, such as "TEFRA HMOs," probably could develop S/HMOs more easily and successfully than other HMOs (841). "TEFRA HMOs" are HMOs participating in Medicare as "risk-contractors" under capitation payment arrangements initiated by the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA). Many TEFRA HMOs already provide more acute and primary care services than Medicare does,[24] but they generally do not provide long-term care services. In May 1988, about 137 of the HMOs participating in Medicare were TEFRA HMOs (840).

S/HMOs derive their revenue from three major sources: 1) per capita payments from the Federal Government for Medicare beneficiaries; 2) monthly premiums (ranging from $29 to $49), deductibles, and copayments from S/HMO members; and 3) per capita payments from State Medicaid programs for S/HMO members who are eligible for Medicaid (270,841). For each of their Medicare members, S/HMOs receive a fixed per capita payment from the Federal Government equal to 100 percent of the average per capita cost of providing comparable fee-for-service benefits for a Medicare beneficiary living in the S/HMO's service area. For each Medicare member found to be "nursing home certifiable"—i.e., to meet the State's criteria for Medicaid-funded nursing home care—the S/HMOs receive a higher per capita payment (270,841).

In the first years of the S/HMO demonstration, the Federal Government and State Medicaid programs shared financial risk with the S/HMO sponsors (2,841). Now the four S/HMOs are at full financial risk for any losses they incur.

Who Is Served

Each S/HMO serves people over age 65 who are eligible for Medicare and choose to enroll in the S/HMO (2,274). As of December 1987, the four S/HMOs had about 15,000 members:

- Medicare Plus II had 4,974 members,
- Seniors Plus had 2,597 members,
- Elderplan had 4,307 members, and
- SCAN Health Plan had 2,840 members (2).

In general, S/HMOs have memberships that are proportionately representative of the overall Medicare elderly population in terms of sex, age, living arrangements, and health status (270,841). About one-third of S/HMO members are elderly people who live alone.

In part because S/HMOs are a Medicare demonstration and in part because the per capita payments S/HMOs receive from the Federal Government are based on the average per capita cost of comparable fee-for-service benefits for Medicare beneficiaries, each S/HMO needs to enroll a membership that is no more functionally impaired than a cross-section of the elderly Medicare population (452). To do so, S/HMOs are permitted to screen their applicants and to "queue" (put on a waiting list) severely and moderately impaired applicants as necessary. Three S/HMOs (Seniors Plus, Elderplan, and SCAN Health Plan) include queuing questions on their application forms and sort clients into functional impairment categories based on their responses to two questions concerning mobility and limitations in activities of daily living (ADLs) (452). These three S/HMOs have been able to maintain a member population that is roughly representative of elderly Medicare beneficiaries in terms of distribution of functional impairment:

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[24] Services that are not covered by Medicare but are offered by some TEFRA HMOs include extra hospital days, annual physicals, and prescription drugs (438,439).

- 80 percent or more of their members are unimpaired or only mildly impaired,
- 7 to 14 percent of their members are moderately impaired, and
- 5 to 8 percent of their members are severely impaired (274,452).

Medicare Plus II has chosen not to queue but also seems to have been able to maintain such a case mix (452).

OTA is unaware of any data on how many people with dementia are members of the four S/HMOs. It is possible, however, that the queuing mechanisms used by Seniors Plus, SCAN Health Plan, and Elderplan prevent some moderately or severely impaired people with dementia from enrolling.

Once an individual is enrolled in one of the S/HMOs, decisions about whether the individual will receive specific S/HMO services are made by various different people. Decisions about acute medical care services are generally made by physicians employed by the HMOs and other organizations that provide these services for the S/HMOs (421). At Medicare Plus II, one of the two S/HMOs sponsored by an HMO, decisions about all services ordinarily covered by Medicare are made by hospital discharge planners, home health agency staff, and others who are employed by or work under contract with the sponsoring HMOs; the S/HMO case managers are responsible for decisions about the additional long-term care services required of S/HMOs but not ordinarily covered by Medicare (2). At Elderplan and SCAN Health Plan, the two S/HMOs not sponsored by HMOs, certain S/HMO case managers are primarily responsible for discharge planning at the hospitals and nursing homes with which the S/HMOs have contracts, and other S/HMO case managers are primarily responsible for decisions about long-term care services for S/HMO members who are not hospitalized or in a nursing home.

The process by which S/HMO case managers make decisions about which S/HMO members will receive S/HMO long-term care services is described briefly below. Ongoing case management is provided for all S/HMO members who receive long-term care services. Thus, the decisions made by S/HMO case managers about which S/HMO members will receive long-term care services also determine which members will receive ongoing case management. OTA is not aware of any data on how many individuals with dementia who are members of S/HMOs receive S/HMO long-term care services and case management. It is likely, however, that certain aspects of the process by which S/HMO case managers decide which S/HMO members will receive long-term care services prevent some people with dementia from receiving services and case management.

At the time of their enrollment in a S/HMO, all S/HMO members are sent a questionnaire on which they are to report basic social, health, and functional information (452). The completed questionnaires are screened by S/HMO case managers using a set of risk criteria to identify which members may need various types of services. Responses that suggest that a member may need long-term care services automatically trigger a phone call by the case manager (see below).

The questionnaire sent to new members is generally reliable for identifying individuals who are severely impaired as measured by the need for assistance with ADLs, but it does not include questions about mental status (270,452). That shortcoming means that responses to the questionnaire are not very useful in identifying individuals with dementia (452). To identify such individuals from the questionnaire, the S/HMO case managers would have to rely on clues, such as apparent confusion in completing the form or the member's use of psychotropic drugs. A shorter version of the questionnaire is sent to members annually. The shorter version includes a question on severe memory loss.

Based on new members' responses to the questionnaire, S/HMO case managers call all the members who the case managers think may need long-term care services—including all members who case managers think may qualify as "nursing home certifiable" (452). These telephone calls are used by the case managers to identify individuals with mental impairments, as well as to verify the information on the questionnaires and provide information for new members about S/HMO services. If a S/HMO case manager concludes, based on the call to a member and the member's questionnaire, that the member does not need long-term care services or does not meet the S/HMO's eligibility criteria for such services, but the individual does seem to be at risk, the case manager may decide that the individual should be monitored, as discussed later in this section.

S/HMO members who the case managers think probably need long-term care services and who probably meet the S/HMO's criteria for long-term care services—including all members who case managers think probably qualify as "nursing home certifiable"—receive an in-home assessment by a S/HMO case manager (452,841). The in-home assessment, which usually takes 45 to 90 minutes, includes the member's health status, functional status, mental status, living arrangements, informal supports, and utilization of services. Following the in-home assessment, the case managers decide which members qualify for S/HMO long-term care services, develop service plans for those members, and arrange the services.

The S/HMOs use three different sets of eligibility criteria to determine which members qualify for S/HMO long-term care services—narrow criteria, broad criteria, and implicit criteria (452). Medicare Plus II and Elderplan have *narrow eligibility criteria*, requiring that their members qualify as "nursing home certifiable" by State standards in order to be eligible for long-term care services (2,452). Different States have different standards for determining who is nursing home certifiable, but in general, the standards identify individuals who are physically or mentally quite disabled (2). In December 1987, 8 percent of Medicare Plus II's enrollees and 4 percent of Elderplan's enrollees qualified as nursing home certifiable (2).

The narrow eligibility criteria used by Medicare Plus II and Elderplan would undoubtedly exclude some members with dementia—for example, those in the early stages of a dementing disease. Furthermore, not all Medicare Plus II or Elderplan S/HMO members who qualify as nursing home certifiable actually receive long-term care services (2). The S/HMO long-term care benefit is intended to supplement but not replace what a member's family or other informal caregivers can do. If a member who qualifies as nursing home certifiable is judged by the S/HMO case manager to have adequate informal supports, that person will not receive long-term care services.

SCAN Health Plan uses *broad eligibility criteria*, requiring only that a member be determined by a case manager to be either moderately or severely impaired (452). Members in these two categories of impairment make up about 20 percent of SCAN Health Plan's membership but would not necessarily include all of the S/HMO's members with dementia.

Seniors Plus uses *implicit eligibility criteria* to determine its members' eligibility for long-term care services (452). This S/HMO formally limits eligibility to members who are nursing home certifiable (about 8 percent of Seniors Plus members in 1987 [2]) but in practice allows the case manager and the director of its case management unit to extend long-term care benefits to other members if they believe that the members are "at risk" and in need of long-term care services. Thus, a person with dementia at SCAN or Seniors Plus might or might not receive long-term care services.

In addition to limitations on eligibility for S/HMO long-term care services, each S/HMO has imposed the following dollar limits on the amount of long-term care services an eligible member may receive. The S/HMO case managers are responsible for keeping expenditures within these limits:

- Medicare Plus II, $12,000 per year, with a monthly cap for each member of $1,000 for community care or 100 days of nursing home care per spell of illness;
- Seniors Plus, $6,500 per lifetime for nursing home care and $5,000 per year for community-based care; Seniors Plus has no set monthly budget cap, but the S/HMO case managers must obtain approval of the S/HMO director prior to authorizing any services costing over $100 per week;
- Elderplan, $6,500 annually, with a monthly cap of $450 per month; and
- SCAN Health Plan, $7,500 per year, with a monthly cap of $625 (2,841).

Data from the first 2 years of the National S/HMO Demonstration show that only a few S/HMO members used enough long-term care services to reach these dollar limits (841).

Linking Functions

Information and Referral

S/HMOs are intended to serve their members, and they do not provide information and referrals to the general public. S/HMO case managers do provide information and referrals for S/HMO members in some instances (2). S/HMO case managers are supposed to refer S/HMO members to free or low-cost community services whenever such services are available and appropriate. For this reason, a S/HMO case manager may refer a S/HMO member to services in the community even if the services are available through the S/HMO. A S/HMO case manager may also refer a member to services in the community if the person needs services that are not included in the S/HMO's benefit package (e.g., legal help, shared housing, home-delivered meals, friendly visitors, senior center) (841). Lastly, if the amount of long-term care services a member receives reaches the dollar limits listed earlier, the S/HMO case manager may refer the member to non-S/HMO services until the benefit renews (usually annually) (2).

Case Management

Case managers play a central role in the S/HMO model of service delivery. As already described, S/HMO case managers determine which S/HMO members will receive long-term care services based on information from a questionnaire completed by each member, a telephone screen conducted by the case managers, and home visits conducted by the case managers. For S/HMO members found to need and be eligible for S/HMO long-term care services, the case managers develop service plans and arrange and coordinate the services. Thus, in the S/HMO model, case managers determine not only which members can receive long-term care services, but also what long-term care services and how much of these services they will receive.

At all four S/HMOs, the case managers are either health professionals, including registered nurses, social workers, and others (e.g., a physical therapist, a speech pathologist), or people with college degrees in human services) (841). As of December 1987, each of the S/HMOs had 5 to 7 case managers with an average caseload of 50 to 71 clients (2).

The case management provided by S/HMOs differs from that provided by many other categories of agencies discussed in this chapter in that it is provided in the context of a service delivery system operating on a capitated, prospectively fixed budget in which there are strong incentives to control the utilization and costs of services (2,270). In such a system, many of the functions of a case manager are essentially administrative tasks related to the operation of the system (e.g., determining an individual's eligibility for services and authorizing the services). S/HMO case managers also perform the five functions that OTA defines as core case management functions—namely: 1) assessing a client's needs, 2) developing a plan of care, 3) arranging and coordinating services, 4) monitoring and evaluating the services delivered, and 5) reassessing the client's situation as the need arises. The way they perform these functions is undoubtedly influenced by the focus of the system on controlling the utilization and costs of services, however.

As noted earlier, all S/HMO members who receive long-term care services also receive ongoing case management. In December 1987, the percentage of S/HMO members receiving long-term care services and case management was 5 percent at Medicare Plus II, 10 percent at Seniors Plus, 2 percent at Elderplan, and 7 percent at SCAN Health Plan (2). OTA does not know what proportion of these individuals had dementia.

Ongoing case management is provided for S/HMO members who are receiving long-term care services to make sure they receive prescribed services and to keep the plan of care updated and cost-efficient (2,518). Contact between the S/HMO case manager and the member or the member's family is often frequent during the first 2 to 3 weeks of a care plan until the plan is fully implemented. Once long-term care services are in place and working well, case managers telephone members and/or their families once a month to once every 3 months to monitor their health status and care needs. At Medicare Plus II, case managers do most of their routine monitoring by telephone and make a home visit every 3 months. At Seniors Plus, most monitoring is done by long-term care providers (e.g., home health aides, nursing supervisors, adult day center staff), who alert the S/HMO case manager if changes occur. At SCAN Health Plan, case managers make monthly home visits to all members with service plans. According to one commentator, the S/HMO case managers also maintain telephone contact with families who live at a distance from a S/HMO member receiving long-term care services, to discuss the member's health status and plan of care—especially if the member is severely impaired (422).

Case managers review selected S/HMO members' health status and plans of care at weekly case conferences, which also serve as a quality assurance and utilization review for services provided under the long-term care benefit package. Case managers are also required to provide each member receiving long-term care services with a comprehensive in-home reassessment every 6 months. Many case managers consider the reassessment process unnecessary because their ongoing, frequent contact with members allows them to reassess members' health status and modify plans of care accordingly, without a formal reassessment (841).

Initially, all four S/HMOs chose to provide case management to some "at-risk" members who were not nursing home certifiable or severely impaired and therefore not eligible for long-term care services but were judged by the S/HMO case managers to need "monitoring" due to an unstable medical or social situation (452,841). Over the course of the demonstration, all four S/HMOs have had to cut back on this practice because of the expense. As of December 1987, the percentage of S/HMO members being "monitored" but not receiving long-term care services was 4 percent at Medicare Plus II, Seniors Plus, and SCAN Health Plan and 3 percent at Elderplan (2).

What is involved in "monitoring" varies from one client to another and from one S/HMO case manager to another, but anecdotal evidence suggests that some S/HMO members who are being "monitored" are receiving what OTA defines as case management. OTA does not know how many individuals with dementia who are members of S/HMOs are being "monitored." As of December 1987, most Medicare Plus II and Elderplan members who were being monitored were nursing home certifiable, whereas at Seniors Plus and SCAN Health Plan, most members who were being monitored were not nursing home certifiable.

Public Education

Each S/HMO offers health education programs to its membership (422). OTA does not know whether any of these programs include information about dementia or services for people with dementia.

To recruit members, the S/HMOs emphasized that they were designed to keep people healthy and in their own homes. Medicare Plus II, the S/HMO most successful in enrolling new members, combined a direct mail campaign with group presentations and poster displays for the community groups and organizations that supported the S/HMO's development. OTA does not know to what extent, if any, these efforts and similar efforts by the other S/HMOs included information about dementia or about the potential value of the S/HMO model of service delivery for people with dementia and their caregivers.

Outreach

S/HMOs serve only individuals enrolled in their programs. S/HMOs do not have outreach procedures to identify non-SHMO members with dementia or their caregivers who are in need of assistance but unlikely to seek help on their own.

As discussed previously, S/HMOs use various procedures (e.g., the initial questionnaire and annual followups) to identify S/HMO members who may need services. OTA does not know how often these procedures identify S/HMO members with dementia who need assistance but are unable to seek it on their own. Anecdotal evidence suggests that such individuals would usually come to the attention of a S/HMO case manager via a referral from a physician, a service provider, or a family member or friend of the individual (422).

All four S/HMOs use case-finding mechanisms in hospitals to identify S/HMO members whose conditions may require long-term care services. Medicare Plus II and Seniors Plus train personnel in hospitals, nursing homes, and home care agencies to identify such individuals and refer them to the S/HMO case managers (452). Elderplan and SCAN Health Plan involve their case managers in discharge planning at the hospitals with which they have contracts. It is important to note, however, that case-finding mechanisms in hospitals are of little value to people with dementia who are not hospitalized.

Role in Allocating Services and Funding

S/HMOs control the allocation of all the health care and long-term care services included in the S/HMOs' benefit package. All allocation decisions are made in the context of the S/HMOs' prospectively determined, capitated budget, in which there are incentives to control the utilization and costs of services.

Summary

As agencies that might be designated to constitute a national system to link people with dementia to services, S/HMOs offer several advantages:

- By providing or contracting for and arranging many of the acute and long-term care services needed by their members, S/HMOs eliminate for their members who receive these services many of the problems in locating and arranging services that are the topic of this OTA report.
- S/HMOs provide comprehensive in-home assessments by case managers (typically registered nurses or social workers) to members who case managers think will require long-term care services.
- S/HMOs provide their elderly members receiving long-term care services with ongoing case management. This includes care planning, coordinating and arranging services, monitoring services, and periodically reassessing the individual's needs. In addition, S/HMOs provide case management in the form of monitoring to some other members who case managers think are at risk.
- S/HMOs build on the concept of HMOs, and it is possible that some of the existing HMOs in this country could be used as a basis for developing more S/HMOs.

Despite these advantages, there are significant drawbacks to designating S/HMOs—as they are currently operating—to constitute a national linking system for people with dementia. One obvious drawback is that there are only four S/HMOs at present. On the other hand, if reimbursement were available through Medicare or other funding sources, HMOs and other agencies would be likely to establish S/HMOs. A second drawback is that S/HMOs serve only their members, and some people with dementia might not be able to join a S/HMO. All but one of the four existing S/HMOs has at various times queued applicants to maintain an acceptable case mix of impaired and unimpaired enrollees. This mechanism may keep some moderately and severely impaired individuals with dementia from joining. Furthermore, S/HMOs serve elderly people exclusively, and some people with dementia are not elderly.

Another problem is that although S/HMOs provide case management for members who are receiving long-term care services, some S/HMO members with dementia—especially members with mild or moderate dementia—are not likely to receive long-term care services and therefore may not receive case management. The process by which S/HMO case managers decide which S/HMO members will receive long-term care services is intended to target the services to the people who are most impaired and therefore most in need of services. Although targeting services to the most impaired individuals may be entirely appropriate, an effective system to link people with dementia to services, including the case management component, must be available to patients and their families throughout the course of the patient's illness. The existing S/HMOs do "monitor" some members who are not so impaired as to be nursing home certifiable, but these individuals constitute only 1 to 3 percent of all S/HMO members.

Lastly, the existing S/HMOs provide little, if any, public education about dementia or about potentially beneficial services for people with dementia and little outreach, except case finding procedures for hospitalized S/HMO members. The extent to which S/HMOs provide their members with information about and referrals to non-S/HMO services in the community is unclear, but providing such information and referrals is clearly not one of the primary functions of S/HMO case managers. If S/HMOs were designated to constitute a national linking system for people with dementia, their public education, outreach, and information and referral activities would have to be expanded.

It is important to keep in mind that the S/HMO is an experiment, and components of the S/HMO model may hold more promise than the specific current implementation of the model in meeting the long-term care needs of the elderly, in general, and of people with dementia, in particular. The S/HMO model is an important demonstration of what HMOs might do in the area of long-term care if Medicare reimbursement were increased specifically for long-term care services.

ON LOK SENIOR HEALTH SERVICES

On Lok Senior Health Services is an organization that plans, coordinates, and provides case management and comprehensive health care, long-term care, social, and other services for about 300 very impaired and frail older adults in the Chinatown-North Beach area of San Francisco (639). All of On Lok's clients have been certified by California's Medicaid program, Medi-Cal, as needing intermediate or skilled nursing home care. Without the services provided by On Lok, many of them would be unable to continue residing in the community (28).

OTA has included On Lok in its analysis of agencies that might constitute a national system to link people with dementia to services because On Lok's comprehensive, consolidated service program exemplifies a model of service delivery that eliminates for its clients the problems in locating and arranging services that are the focus of this OTA report.

The On Lok model, in which a single organization provides or contracts for virtually all the health care and health-related services its clients need, can be contrasted with the more traditional model of case management and service delivery in which a case manager refers individuals who need health care, long-term care, social, and other services to agencies and individual service providers in the community (639). The On Lok model is similar to the social health maintenance organization (S/HMO) model discussed in the previous section of this chapter in that it provides services to voluntarily enrolled individuals in exchange for a fixed per capita payment, but On Lok provides a wider range of long-term care, social, and other services than S/HMOs provide. Another difference between On Lok and S/HMOs is that S/HMOs serve a full spectrum of healthy and impaired people over age 65 (3), whereas On Lok serves only severely impaired adults over age 55.

Overview of the Agency

On Lok's program began in 1972 and has expanded over the years. In 1972, On Lok received a 3-year research and demonstration grant from the Administration on Aging to establish an adult day health center (633,940). In 1975, On Lok got another 3-year grant from the Administration on Aging, this time to expand its adult day health program and to provide a variety of other services (e.g., in-home chore services, home-delivered meals, and housing assistance)—all of which were to be delivered or supervised by a multidisciplinary team (634). In 1978, On Lok got a 4-year grant from the Office of Human Development Services in the U.S. Department of Health and Human Services to plan and implement a comprehensive, consolidated, long-term care program for dependent adults (635).

From 1979 to 1983, On Lok operated as a Medicare demonstration program with funding through Medicare waivers; during that time, On Lok received per capita payments for the care of its clients from Medicare, but the payments were based primarily on the costs that On Lok incurred (942). In 1983, On Lok assumed full financial risk for providing all health care and health-related services for its clients in exchange for a fixed per capita payment. On Lok has both Medicare and Medicaid waivers to allow the provision of comprehensive services and for its risk-based financing system.

Currently, On Lok operates three adult day health centers. These adult day health centers are open 7 days a week and are the primary setting in which On Lok's clients receive services. On Lok also has a home health care department that provides in-home services, including home health care, personal care, hospice, and respite care for On Lok clients who need these services (639). Through its adult day health and home care programs, On Lok has the capacity to monitor any client on a 24-hour basis.

About three-quarters of On Lok's clients live alone (28,639). Many of them live in congregate housing provided by organizations affiliated with On Lok. Such housing includes the 54-unit On Lok House, which is subsidized by the U.S. Department of Housing and Urban Development, and a 35-unit single room occupancy hotel, which is privately funded. For some clients, On Lok arranges housing in private residences.

Although On Lok's goal is to enable its clients to continue residing in the community, On Lok arranges and pays for inpatient hospital care or nursing home care for its clients who need either type of care (639,942). On Lok has contracts with local hospitals and nursing homes to provide the needed care, but On Lok retains responsibility for its clients who are hospitalized or in a nursing home. On Lok's physicians manage the care of these clients, and other On Lok staff members visit the clients regularly to monitor their care (639, 942). On Lok clients who are in a nursing home usually continue to attend On Lok's adult day health centers 1 or 2 days a month (639).

As mentioned earlier, On Lok has operated on a risk-based financing model since 1983 (636,639). On Lok receives a fixed, per capita payment for each client. The payment is received from Medicare, Medi-Cal, and/or the client (depending on whether the client is eligible for Medicare and Medi-Cal). When the cost of services is higher than the payment On Lok receives, On Lok absorbs the loss. When the cost of services for an individual client is higher than the payment On Lok receives, On Lok places the excess revenue in a risk reserve fund to pay for cost overruns (28).

For fiscal year 1988, On Lok received an average monthly payment of $2,156 per client (28). Most of On Lok's clients are eligible for Medicare, and for these clients Medicare pays 36 percent of the per capita payment to On Lok; the remaining 64 percent is paid either by Medi-Cal (for clients who are eligible for Medi-Cal) or by the client. Clients who are unable to pay for part or all of their portion of the payment due to special family circumstances may be eligible for "scholarships" through a United Way allocation (639). As of the last quarter of fiscal year 1987, Medicaid payments accounted for about two-thirds of On Lok's $7.2 million annual budget; Medicare payments accounted for just under one-third, and other sources, including clients and the United Way, made up the remainder (640,780).

Efforts to expand On Lok's model of community-based long-term care to other areas of the country are underway. In the Omnibus Budget Reconciliation Act of 1986 (Public Law 99-509), Congress authorized the Health Care Financing Administration to grant On Lok-type waivers to as many as 10 replication sites. In 1987, the Robert Wood Johnson Foundation committed $4.2 million in startup funds for six On Lok replication sites and gave On Lok $1.6 million to provide technical assistance to prospective replication sites (638). In 1987, the Hartford Foundation pledged an additional $600,000 to On Lok to provide technical assistance in the replication project (637).

Nearly 180 organizations expressed interest in participating in the On Lok replication project. Six replication sites were selected in 1987: the East Boston Neighborhood Health Center in Boston, Massachusetts; Beth Abraham Hospital in Bronx, New York; Providence Medical Center in Portland, Oregon; the Richland Memorial Hospital in Columbia, South Carolina; Bienvivir Senior Health Services in El Paso, Texas; and the Community Care Organization in Milwaukee, Wisconsin.

On Lok continues to work with other sites interested in participating in the replication effort.

Who Is Served

As noted earlier, On Lok currently serves a population of about 300 severely impaired and frail older adults (3). To be eligible for On Lok services, individuals must meet the following criteria:

- be 55 years or older,
- reside in On Lok's 3.5-square-mile catchment area in northeast San Francisco, and
- be certified by Medi-Cal as requiring intermediate or skilled nursing home care (639).

During the first 2 years of On Lok's operation as a Medicare demonstration project, the application of these criteria eliminated over 80 percent of all referrals (941), and On Lok had a difficult time securing an adequate number of clients. Other reasons for On Lok's difficulty in securing clients included the inability of many severely impaired elderly people to seek help from On Lok on their own, the unwillingness of some physicians to refer their patients to On Lok and thus relinquish control of the patients, and the reluctance of many elderly people to change their health care arrangements unless motivated to do so by the development of an acute illness (941). On Lok has found that securing an adequate number of clients requires continuing efforts to educate the community about On Lok's services and advantages for potential clients (28).

According to a client profile published in 1988, the average On Lok client is 81 years old and has five serious medical conditions (639). About 58 percent of On Lok's clients are female, and 42 percent are male. More than 80 percent of On Lok's clients are of Chinese descent; 4 percent are Italian; 2 percent are Filipino; and the rest are of other backgrounds (640). On Lok clients' average monthly income is $535; 68 percent receive Supplemental Security Income (640). As noted earlier, about 75 percent of On Lok's clients live alone, either in their own homes or in congregate housing. The other 25 percent live with others in the community. About 70 percent of clients require assistance with bathing, 68 percent with home care, 64 percent with cooking, and 51 percent with grooming and hygiene (639).

Many On Lok clients have cognitive impairments. According to On Lok's figures, 85 percent have short-term memory problems, and 80 percent have long-term memory problems (640). Thirty-eight percent have a diagnosis of a mental disorder.

Linking Functions

Information and Referral

On Lok's primary objective is the provision of comprehensive health care, long-term care, social, and other services to its own severely impaired clients. On Lok is not currently oriented toward providing information and referrals for the general public.

Case Management

All of On Lok's clients receive case management. Each person referred to On Lok is assessed by a multidisciplinary team that includes a physician or nurse practitioner, a social worker, a nurse, physical and occupational therapists, and others (942). If warranted, the assessment may also involve a psychiatrist and other medical specialists. Following a comprehensive assessment, a representative from the State Medicaid office certifies or declines to certify the individual as needing intermediate or skilled nursing home care (639).

If an individual is certified as needing intermediate or skilled nursing home care and meets On Lok's other eligibility criteria, he or she is accepted into On Lok's program. On Lok's clients receive ongoing case management by On Lok's multidisciplinary team. The case management includes the development of a plan of care by the multidisciplinary team that assessed the client, and the subsequent coordination, arrangement, and monitoring of all the health care, long-term care, social, and other services that the client receives (942). It also includes the reassessment of each client at regular intervals. Most clients are reassessed every 3 months, although clients whose conditions are considered stable are reassessed less frequently (e.g., every 6 months).

Public Education

To OTA's knowledge, On Lok does not provide information for the general public about dementia or services for people with dementia. As noted earlier, On Lok has found that securing an adequate number of clients requires continuing efforts to educate the community about On Lok's services (28). To inform the community about its services, On Lok sponsors public service announcements over the local media, places ads on buses, and participates in an annual health fair in the Chinatown area of San Francisco (940). On Lok's staff also participate in local and national conferences and meetings, where they present information about On Lok's experience with case management, health care financing, and alternative long-term care service delivery systems (28,940).

Outreach

Typically, On Lok serves clients who have been referred by various sources, including families, physicians, hospital discharge planners, other community agencies, and family associations (28). A few referrals have resulted from On Lok's participation in a local group called the Coalition of Agencies Serving the Elderly. Recently, On Lok's social workers have been visiting local apartment houses and public housing complexes to reach isolated, elderly people who might benefit from On Lok's services, but are unlikely to learn about the services through On Lok's community education efforts or to be referred to On Lok by other sources.

Role in Allocating Services and Funding

Unlike most of the other agencies discussed in this chapter, On Lok controls the allocation of all health care, long-term care, social, and other services for its clients. All services for each client are planned and

Photo credit: On Lok Senior Health Services

Recently, On Lok's social workers have been visiting local apartment buildings and public housing complexes to reach isolated, elderly people who might benefit from On Lok's services but are unlikely to contact the agency on their own or to be referred to On Lok by another source.

coordinated by On Lok's staff and directly provided by On Lok's multidisciplinary team, by authorized consultants, or by contractors (639).

Summary

As an agency that might be designated to serve as the basis of a national system to link people with dementia to services, On Lok offers several positive features:

- By providing virtually all the health care, long-term care, social, and other services that are needed by its clients, On Lok eliminates problems they might otherwise have in locating and arranging services.
- On Lok provides a comprehensive, multidisciplinary assessment for the individuals who are referred to it.
- On Lok provides ongoing case management, which includes care planning, coordinating and arranging services, monitoring services, and periodically reassessing the individual's needs.
- On Lok has the capacity to serve individuals on a 24-hour basis.

Although On Lok essentially eliminates for its clients the problems in locating and arranging services that are the focus of this OTA report, the On Lok model is not an appropriate model to use as the basis of a national system to link people with dementia to services. As currently structured, the On Lok model is intended to provide case management and comprehensive services to a small population of severely impaired and frail older adults who have been certified as requiring intermediate or skilled nursing care. The On Lok model is not intended to provide information and referrals or case management for people who are less severely impaired (e.g., people in the early and middle stages of dementia) or for their caregivers.

Clearly, On Lok is an effective service system for its clients, and the large number of organizations nationwide that expressed an interest in participating in the On Lok replication program attests to the enthusiasm many service providers feel about this innovative model of service delivery. Moreover, there is little doubt that On Lok's clients with dementia are receiving the care they need. To expand On Lok's functions to include providing information and referrals and case management for people with dementia who are not as severely impaired as On Lok's current clients or who do not need the comprehensive services On Lok provides, would require a significant change in direction and priorities for the organization, possibly to the detriment of the model service system it has created.

ADULT DAY CENTERS

Adult day centers are community organizations that provide a range of health care, social, and other services to small groups of functionally impaired adults in group settings during specified hours of the week. By providing services in a group setting for these functionally impaired adults, adult day centers also give the individuals' primary caregivers a temporary respite from the demands of caregiving.

The National Institute on Adult Daycare, a membership organization composed of professionals in the field of adult day care, has estimated that as of 1989 there were at least 2,500 adult day centers in the 50 States, the District of Columbia, and Puerto Rico (940). Most of the centers are located in cities and other densely populated areas (488).

OTA has included adult day centers in its analysis of agencies that might constitute a national system to link people with dementia to services because many adult day centers serve people with dementia, and anecdotal evidence suggests that the staff of some of these centers have come to be regarded as local experts on what services are beneficial for people with dementia and their caregivers and where such services can be found. As a result, some health care and social service professionals, service providers, and family caregivers turn to them for information and referrals for people with dementia. Furthermore, the Robert Wood Johnson Foundation is currently sponsoring a demonstration project in which the goal is to create a comprehensive system of care for demented people and their caregivers that relies on adult day centers to coordinate the care (717).

Overview of the Agencies

Adult day centers were established in the United States as the result of a grassroots movement to develop services that would enable functionally impaired adults to remain in their own homes rather than be institutionalized (879). Although a small number of adult day centers were established before 1970, most have been established since then. In part, because of their grassroots origins, adult day centers vary considerably with respect to the organizations with which they are affiliated, the settings in which they operate, the content and structure of their programs, and the clientele they serve (879). Adult day centers are not subject to Federal regulation, although some adult day centers provide services that are reimbursed by Medicaid or Medicare, and those services are subject to Federal regulation (831). The lack of Federal regulation contributes to the variation among centers.

In 1979, the National Council on the Aging established the National Institute on Adult Daycare to open communication among adult day centers throughout the country and to coordinate activities for the further development of adult day programs and services (879). In 1984, the institute published voluntary national standards for adult day centers, and in 1988, the institute began revising the standards in an effort to reflect the special needs of clients with Alzheimer's disease and other dementing disorders (579).

Adult day centers vary greatly in the services they provide. Some adult day centers provide primarily health care services, and some centers provide primarily social and personal care services. Most provide some combination of social services, nursing, recreational activities, exercise, reality therapy, personal care, and nutrition counseling (879). Although most centers do not provide their clients with a medical evaluation, some centers can arrange for a medical diagnosis or a second opinion for their clients (336,940). Some centers also provide or contract for physical therapy, speech therapy, occupational therapy, psychotherapy, and legal and financial counseling (879). During the time clients are at an adult day center, the center's staff are able to monitor their functional, psychosocial, and general health status on an ongoing basis (336,940). Many centers also offer services for their clients' families and other informal caregivers, such as counseling, caregiving training, caregiver support groups, and information about services and sources of funding for services (606).

Some adult day centers offer services for a few hours a day (e.g., 9 a.m. to 3 p.m. or 10 a.m. to 1 p.m.), 5 days a week (606). Other centers offer services for a few hours a day, 2 or 3 days a week. Still other centers offer services for part of the day only 1 day a week. In some cases, people with dementia who need constant supervision or who may be upset by an interruption in their daily routine attend an adult day program 7 days a week (940),[25] but most adult day programs do not operate on a 7-day schedule, so this option is not always available (606).

Most adult day centers are operated by private, nonprofit agencies (879), but some are operated by public agencies, and a few are operated by private, for-profit agencies. Many adult day centers share facilities with other programs. Settings for adult day centers include hospitals, churches, senior centers, community centers, elderly housing projects, and nursing homes. Nurses and social workers are the most commonly reported paid professional staff of adult day centers and often serve as a center's director (879). Physicians or psychiatrists may sometimes be available as part-time consultants. Other professionals and laypersons sometimes serve as volunteers.

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[25] On Lok Senior Health Services, described in the previous section, evolved from an adult day center and offers adult day services 7 days a week (639).

As of 1986, the average daily cost of providing adult day services was about $31 per client (879). The two main sources of funding for adult day services are Medicaid and participants' fees. Medicaid reimbursement for adult day services is available at the option of individual States; a nationwide survey by the National Institute on Adult Daycare, completed in 1988, found that 25 States were providing coverage for adult day services under Medicaid (580). People who are not eligible for Medicaid usually pay for adult day services out-of-pocket (879). Some centers allow participants to pay fees based on a sliding fee scale related to their incomes (606). Additional funds may be provided by sources such as foundation grants, individual donations, fundraising projects, and United Way (879). Some funds are also provided by States under the Older Americans Act, the Social Services Block Grant, and Medicaid 2176 waivers.[26] As of 1989, proposed Federal legislation to cover adult day services under Medicare had not been enacted (although Medicare does sometimes pay for health care services, e.g., physical therapy, provided by some adult day centers) (606). Most private insurers do not cover adult day services (879).

Who Is Served

In 1987, it was estimated that existing adult day centers served less than 1 percent (about 4,000) of the noninstitutionalized people with dementia in the United States (717). As the demand for adult day services for people with dementia increases, however, some adult day centers are modifying their programs to accommodate clients with dementia. An analysis of a program offered by an adult day center in Gardena, California, that has adapted its program to include people with dementia, concluded that adult day centers can successfully adapt their programs to meet the needs of adults with dementia (126).

Many adult day centers serve a mixed clientele with both demented and nondemented people. A 1985-86 survey by the National Institute on Adult Daycare did not ask specifically about dementia but did ask about client characteristics that may be related to dementia, such as supervision needs (879). Data from the 847 adult day centers that responded to the survey show that 45 percent of their clients required supervision, and 20 percent required constant supervision.

One example of an adult day center that serves a mixed clientele with some demented patients is the Woodside Senior Assistance Program in Woodside, New York (606). This program serves about 25 persons over the age of 50, approximately 20 percent of whom are "non-wandering, relatively early stage Alzheimer's patients." Another example of a center that serves a mixed clientele with some demented patients is the Sea View Hospital and Home Adult Day Services Program in Staten Island, New York. This program serves adults over the age of 21, about 10 percent of whom have Alzheimer's disease and participate in separate as well as combined activities.

Although most adult day centers that serve people with dementia also serve nondemented people, a small but increasing number of adult day centers serve only people with Alzheimer's disease and other dementing illnesses (605,740). Dementia-specific adult day centers usually serve a smaller number of participants than centers with a mixed clientele (717). One dementia-specific center, the Family Respite Center in Virginia, is described in box 8-P.

The number of demented individuals who are able to use adult day services is limited for several reasons. One reason is that existing adult day centers tend to be located in cities or other densely populated areas (488). People with dementia who do not live near a center may be unable to attend because they lack transportation or are unable to commute to the center because of distance. One commentator has noted that some people with dementia become anxious and agitated during long commutes (488).

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[26] Centers that receive Medicaid funds tend to have a health care orientation, whereas centers that rely on Social Services Block Grant funds tend to have a social services orientation (824).

Box 8-P—The Family Respite Center in Falls Church, Virginia

The Family Respite Center is a nonprofit adult day center in Falls Church, Virginia, that has been serving demented people and their caregivers since 1984. The center occupies two large rooms with adjoining bathrooms and kitchen facilities in a local church. It operates from 7:30 a.m. to 5:30 p.m. on weekdays and serves a maximum of 20 clients each day. The center has offered in-home respite care since March 1988 on an hourly and overnight basis.

Funding for the Family Respite Center comes from private donations and clients' fees. Four clients are eligible for Social Services Block Grant funds, and two participants attend on scholarships. The local AAA funds the meal component of the program and cooperates with other community agencies to provide transportation to the center.

Clients are referred to the Family Respite Center by various sources that include physicians, hospitals, the Department of Social Services, the AAA, community groups such as the Alzheimer's Association, the American Association of Retired Persons, local churches, private home care agencies, and the Madison Adult Day Care Center operated by Arlington County, Virginia.

The Family Respite Center offers a comprehensive program of therapeutic physical and social activities to maintain or improve the physical and mental abilities of demented clients. Each participant is under the care of his or her family doctor, who is kept informed of the patient's status. In addition to informally monitoring each participant's behavior and health, the center reassesses each participant's functional status every 3 months. The center's medical director is a neurologist, who is available to consult with both staff and family caregivers. The center also offers education programs for caregivers, volunteers, and service providers and conducts a support group twice a month for family caregivers.

The Family Respite Center does serve people with dementia who are incontinent, who may be disruptive, or who have a history of combativeness. The center also serves people with dementia without immediate family to care for them, providing that they have friends or other individuals who can transport them to the center and provide other services needed to enable them to reside in the community.

Having acquired a reputation via the grapevine as a knowledgeable source of information and referrals, the Family Respite Center receives an average of two inquiries a day from families seeking information about Alzheimer's disease and appropriate services for a family member. Referrals to other services are based on the director's knowledge of local resources and of the experiences of other clients. No formal recommendations are made, and clients are encouraged to evaluate all services before using them.

SOURCE: L. Noyes, director, Family Respite Center, Inc., Falls Church, VA, personal communication, Apr. 12, 1988.

Another reason the number of demented individuals who are able to use adult day centers is limited is that most centers have eligibility criteria that exclude certain potential clients. Eligibility criteria vary from center to center (336,606,879,940). Some centers serve all adults over the age of 21 who meet other specified criteria, whereas others serve only those over the age of 55 or 65. Some centers restrict eligibility to people from certain geographic areas; others impose no geographic restrictions. Some centers restrict eligibility on the basis of functional impairment, and other adult day centers serve people with severe functional impairments (304,690).

Eligibility criteria that exclude people who are incontinent, behaviorally disruptive, or combative are likely to exclude some people with dementia. In response to the 1985-86 survey of 847 adult day centers by the National Institute on Adult Daycare, 35 percent of the centers reported that they had excluded people with unmanageable incontinence; 30 percent reported that they had excluded people who were behaviorally disruptive; and 12 percent reported that they had excluded people who were combative (879). Five percent of the 847 centers reported that they had excluded people they considered "too confused," and 5 percent reported that they had excluded people who needed constant supervision. Many of the 847 responding centers indicated that decisions about whether to allow individuals to participate in their programs were often made on a case-by-case basis, depending on factors such as the severity of an individual's functional impairment and the compatibility of an individual's needs with those of other clients.

Even some dementia-specific adult day centers have eligibility criteria that exclude certain people with dementia. The Adult Day Services Program of the Hebrew Home for the Aged in the Bronx, New

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York, serves people aged 55 or over with a diagnosis of Alzheimer's, multi-infarct dementia, or Parkinson's disease; the program does not accept people with unmanageable incontinence or wandering behavior (606). In contrast, another dementia-specific program, the Alzheimer's Day Care Program of Morningside House in the Bronx, New York, admits people of all ages and does accept persons who are incontinent (606).

Some adult day centers do not serve people with dementia who live alone and do not have a family or other caregiver to supervise them when the center is closed (488,606). The following anecdote illustrates how the staff of one adult day center worked with a local church to enable a client with Alzheimer's disease who had no family caregiver to remain in the community.

> Paul, who suffers from Alzheimer's disease, lives alone and has no immediate family to look after him. He is a member of a local church, however, and church members have taken an interest in his well-being. Some time ago, with the help of church members, Paul was enrolled in an adult day program. Steve, a young man who is a member of Paul's church, agreed to transport Paul from his apartment to the adult day center.
>
> At one point, the local adult protective services agency became concerned about Paul's safety during the hours he wasn't at the adult day center. Adult protective services staff were particularly worried that Paul might wander at night and recommended that he be placed in a nursing home. The adult day center staff objected to this recommendation, because their experience with Paul indicated that once Paul fell asleep, he slept soundly. Steve indicated that he was willing to remain overnight with Paul when Paul was restless, anxious, or unable to fall asleep easily. The staff at the adult day center were convinced that with Steve's assistance, Paul was capable of remaining in the community.
>
> Eventually, the adult protective services agency took Paul's case to court. The adult day center staff were able to convince the court that Paul was capable of functioning safely in the community. The adult day center staff are now trying to find a new apartment for Steve and his family that would also accommodate Paul (617).

As this anecdote suggests, adult day center staff are often highly dedicated people who become very involved in the well-being of their clients and are willing to "go the extra mile" to help their clients get the services they need.

Linking Functions

Information and Referral

Although adult day centers generally have no formal mechanisms for providing their clients and clients' families with information and referrals to other community agencies, many adult day centers do provide clients and their families with information and referrals on an informal basis. Some centers also refer their clients to local AAAs, Alzheimer's Association chapters, or other agencies for information and referrals to community services (485, 617,940).

Adult day centers have no formal mechanisms for providing people other than their clients and clients' families with information and referrals to community services, but staff members at some adult day centers that serve people with dementia do provide information and referrals to people other than their clients on an informal basis (485,517,940). These staff members are likely to learn from various sources about services that are used by people with dementia and their caregivers. They may hear about services their clients have used or learn about services through their efforts to help their clients find other sources of assistance. Some staff members at adult day centers come to be perceived as local experts on services for people with dementia, and other health care and social service providers may call them for information and advice. Families of people with dementia may also be referred to them, sometimes for adult day care, but often for information about other community services.

Case Management

Adult day centers generally do not provide their clients with formal case management, but frequent personal contact with clients and their families provides staff members an opportunity to informally assess the needs of clients and their families, suggest appropriate services, and help the family locate and arrange services (485,617,940). Such staff members generally have limited time and resources for formal followup, but clients and their families are likely to report back informally on the success or failures of referrals they have received.

As noted earlier, the Robert Wood Johnson Foundation is sponsoring a $7.5 million project, the Dementia Care and Respite Services Demonstration, with the goal of creating a comprehensive system of care for demented people and their caregivers in which adult day centers serve as the central coordinating element (717). In 1988, the foundation, in conjunction with the Alzheimer's Association and the Administration on Aging, selected 19 adult day centers nationwide to participate in the demonstration project (712). Each adult day center participating in the project will receive grants of up to $300,000 over a 4-year period to enhance its services for dementia clients and their caregivers. The Robert Wood Johnson Foundation has found that adult day centers "become 'community centers' for providing and facilitating the range of services needed by people with dementia and their caregivers." Each center participating in the demonstration project is required, among other things, to "develop a case-coordinated plan for each client and caregiver to assure access to requested services through direct provision or referral to other community agencies." The results of the demonstration will have implications for the role of adult day centers in providing case management, respite, and other services for people with dementia and their caregivers.

Public Education

Adult day centers promote their own services and adult day services in general in various ways, including advertising in local newspapers, telephone directories, and community publications and participating in community forums, information fairs, and similar public events. Anecdotal evidence indicates that some dementia-specific adult day centers use similar methods to educate the public about Alzheimer's disease and related dementias and about adult day care as a potentially beneficial service option for people with dementia (485,617).

Outreach

Most adult day centers do not have sufficient staff or resources to conduct active outreach to identify people who might benefit from their services but are unlikely to be referred or to contact an adult day center on their own (617). On the other hand, some adult day centers send staff to visit elderly housing facilities in the community to seek out people who would benefit from an adult day program (336,940).

Role in Allocating Services and Funding

Adult day centers do not control access to, or funding for, services other than those they provide.

Summary

As agencies that might be designated to constitute a national system to link people with dementia to services, adult day centers offer the following advantages:

- Adult day centers that serve at least some people with dementia may have a nurse, social worker, or other staff member who is knowledgeable about community services for people with dementia and is able to provide information about such services to clients of the center and other people who contact the center.
- Adult day center staff often are highly dedicated people who are very concerned about their clients' well-being and are often willing to "go the extra mile" to help their clients get the services they need.

Although adult day programs are a vital component of community-based, long-term care and provide obvious benefits for some demented adults and their caregivers, it is unlikely that adult day centers could serve as the basis of a national system to link people with dementia and their families to services. The major reason is that although adult day centers provide information and referrals and informal case management for their own clients, such centers currently serve only a small percentage of people with dementia in this country, and most adult day centers do not have the resources to provide information and referrals or case management for people other than their own clients. To have adult day centers take on the task of linking demented people and their caregivers to services would require a significant redefinition of the centers' institutional mission and an infusion of additional resources.

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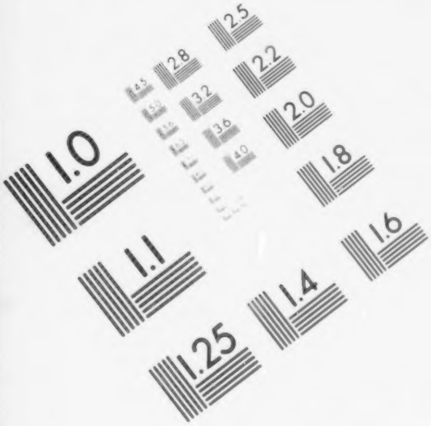
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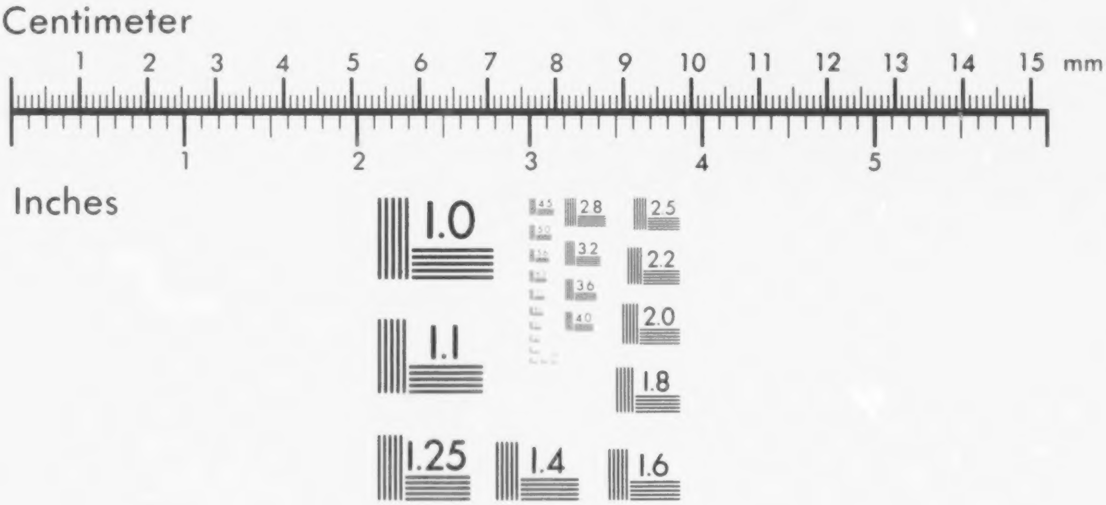
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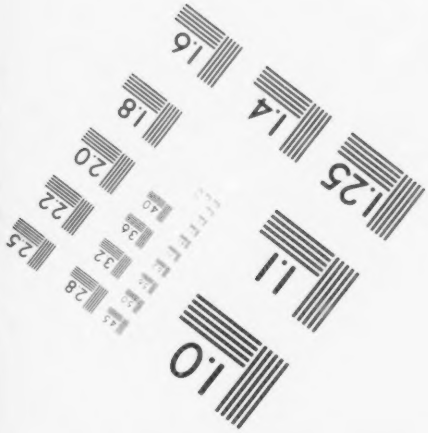
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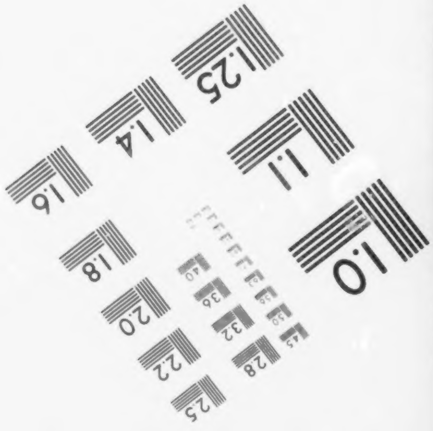
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Appendixes

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Appendix A
Method of the Study

Following the release of OTA's report, *Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias*, in April 1987, OTA received a number of requests for a follow-on study of methods of locating and arranging services for people with dementia. The follow-on study was requested by the Senate Committee on Labor and Human Resources, Senator Charles E. Grassley, the House Committee on Energy and Commerce, and the House Select Committee on Aging. OTA received letters of support for the study from the Senate Special Committee on Aging, Senator Frank H. Murkowski, ranking minority member of the Senate Committee on Veterans' Affairs, the House Committee on Veterans' Affairs, and Congresswoman Olympia J. Snowe. In response to these congressional requests, OTA staff developed a proposal for the study, and the Technology Assessment Board approved the proposed study in June 1987.

In conducting a study, OTA generally relies on the advice and assistance of an advisory panel. The advisory panel suggests source materials, subject areas, and perspectives to consider; reviews drafts prepared by staff and contractors; helps interpret information, suggests conclusions based on the information prepared by staff; and offers advice in the development of policy options. The advisory panel for this OTA study was selected in October 1987. The 21 members of the panel were chosen to represent the professions and types of agencies and organizations involved in caring for people with dementia and locating and arranging services for them. The panelists included some individuals whose work focuses specifically on people with dementia and some individuals whose work focuses on elderly and/or disabled people in general and includes people with dementia in those categories. David F. Chavkin, of the American University Practicing Law Center, served as the panel chair. The members of the panel are listed at the beginning of this report. Between January and November 1988, three panel meetings were held. The panel meetings were open to the public, and some observers attended each meeting.

The first advisory panel meeting was held January 7, 1988. Panel members discussed the overall direction and plan for the study and examined some of the relevant definitional issues, particularly the definition of case management. The panel also helped OTA staff identify the types of agencies and providers that should be analyzed in the report with regard to their capacity to link people with dementia to services.

The second panel meeting was held on June 23, 1988. At that meeting, partial drafts of several chapters of the report were reviewed, and it was decided that a separate chapter on making decisions about services for people with dementia would be needed. In addition, after much debate, the panel concluded that an effective system to link people with dementia to services must include four components, i.e., public education, information and referral, case management, and outreach.

The third and final panel meeting was held on Nov. 3-4, 1988. The primary focus of that meeting was the draft of the final report prepared by OTA staff. The panel discussed its strengths and weaknesses and made recommendations for changes and improvements. The panel also discussed the policy options for congressional consideration, particularly whether a system to link people with dementia to services should serve people with dementia exclusively or people with other diseases and conditions as well.

Following the third panel meeting, the report was revised by OTA staff to reflect the comments and suggestions of the advisory panel and then sent to about 60 outside reviewers, including individuals from Federal, State, and local government agencies that have programs that link people with dementia to services, private agencies and organizations, health care and social service professionals, service providers, Alzheimer's advocates, and others. The report was again revised to reflect the comments and suggestions of these outside reviewers. It was submitted to the Technology Assessment Board in July, 1989.

Early in the assessment, because of the lack of available information about several important aspects of the process by which people with dementia are—or are not—connected to appropriate services, OTA contracted for four small, exploratory studies, the findings of which are discussed in the report. The four studies are described briefly below. Due to the small size of the samples and other characteristics of the four studies, their findings cannot be generalized with certainty, but they do provide insight into the problems families and others experience in locating and arranging services for a person with dementia and the possible solutions for those problems.

A full report on each of the studies is available from the National Technical Information Service, U.S. Department of Commerce, 5285 Port Royal Rd., Springfield, VA 22161, phone (703) 487-4650. The publication number for each of the contract reports is noted below.

1. In 1987-88, a multifaceted exploratory study was conducted for OTA in Cuyahoga County, Ohio, to learn about the sources of information and referrals and other aspects of the process by which families and others locate services for a person with dementia. The study was directed by Sharen K. Eckert of the Cleveland Chapter of the Alzheimer's Association and Kathleen Smyth of

University Hospitals of Cleveland. It had five components:

- The contractors identified all the public and private agencies in Cuyahoga County that they thought might provide information, referrals, or services of any kind for people with dementia; the contractors developed and mailed a questionnaire to each of the 324 agencies they identified; 97 questionnaires were completed and returned, and their results were analyzed.
- In-depth interviews were conducted with representatives of 24 of the 75 agencies that indicated on their questionnaire that they provide information and referrals for people with dementia.
- OTA's contractors analyzed information about the people who called the telephone information and referral helpline of the Cleveland Alzheimer's Association Chapter between April and June 1988.
- Indepth interviews were conducted with 26 caregivers who contacted the helpline in that time period and received a referral to a specific service provider.
- Information about people who called the telephone helpline of the Benjamin Rose Institute in Cleveland was analyzed to compare the information and referral needs and experiences of people who called the helpline for someone with a physical impairment v. people who called the helpline for someone with a mental impairment.

The findings of the study conducted for OTA in Cuyahoga County, Ohio, are discussed primarily in chapter 2 but also in chapters 1, 3, 5, and 8. A full report on the study, "A Case Study of Methods of Locating and Arranging Health and Long-Term Care Services for Persons With Dementia," is available from the National Technical Information Service, #PB 90-186933.

Following the completion of the study in Cuyahoga County, OTA staff met with the contractors and several other individuals who are familiar with the service environment for people with dementia in the county to discuss the study's findings and their implications for an effective system to link people with dementia to services. Involved in that meeting were Sharen K. Eckert and Peg Kuechle of the Cleveland Chapter of the Alzheimer's Association, David Bass and Linda Noelker of the Benjamin Rose Institute, and Kathleen Smyth and Peter Whitehouse of University Hospitals of Cleveland.

2. To explore the question of what is different or special about case management for people with dementia, OTA contracted for an exploratory study of case managers' views regarding the unique aspects and difficulties of working with people with dementia and their families and family caregivers' views regarding the process by which case managers arrange services for their relative with dementia. The study was conducted for OTA by Steven H. Zarit, Eileen MaloneBeach, and Diana L. Spore of Penn State University.

The study was carried out in 4 counties in central Pennsylvania and involved in-depth interviews with 15 staff members from 5 area agencies on aging (AAAs) and 46 family caregivers of people with dementia. The 15 AAA staff members who were interviewed for the study included the case management supervisor and two other staff members selected by the supervisor at each AAA; the staff members selected by the supervisors included eight case managers and two case aides. The 46 family caregivers who were interviewed included some caregivers who were identified by the AAA case managers and some who were recruited independently. The primary sources of the independent sample were support groups, a day care program, and other subjects. The interviews with the AAA staff members and the family caregivers were based on interview schedules developed by OTA's contractors.

The findings of the study are discussed primarily in chapter 3. A full report on the study, "Case Management as an Approach to Dementia: An Exploratory Study," is available from the National Technical Information Service, #PB 90-123191.

3. To learn about how ethnic minority people with dementia are linked to services and to identify any special problems that may arise in the linking process for them, OTA contracted for an exploratory study that was carried out in Los Angeles and San Diego Counties, California. The study involved interviews with the families and other informal caregivers of black, Hispanic, Japanese, and American Indian people with dementia and with staff members of agencies that provide services for people in the four groups. The study was directed by Ramon Valle of San Diego State University, Lourdis Birba of American Health Geriatric Systems in Los Angeles, Josephine Yelder of Pepperdine University, Yasako Sakamoto-Kowalchuk of Little Tokyo Service Center, Ralph Forquera of the American Indian Health Center, Rose Cosgrove of the Indian Health Council, Inc., Rincon Reservation, and Denise Nelsen of San Diego State University.

In all, 88 ethnic minority caregivers were interviewed, including 35 blacks, 25 Hispanics, 18 Japanese, and 10 American Indians. Forty-eight staff members of agencies that provide services for the four ethnic minority groups were interviewed. The interviews were based on interview schedules developed by OTA's contractors. The interview schedule for the caregivers was translated into Spanish and Japanese, and the interviewers for the Hispanic and Japanese caregivers were bilingual.

The findings of the study are discussed primarily in chapters 1 and 2. A full report on the study, "Linking of Ethnic Minority Elderly With Dementia to Long-Term

Care Services" is available from the National Technical Information Service, #PB 90-186446.

After OTA's contractors compiled the results of the interviews, the contractors and OTA staff met with some of the interviewers and local service providers for three of the four groups—blacks, Hispanics, and Japanese—to discuss the study findings and their policy implications. It was not possible to arrange a meeting with the American Indian service providers in the time available for the study. Participants in the meetings, held in Los Angeles in December 1988, were: Yasako Sakamoto-Kowalchuk and Yosh Bill Watenabe of the Little Tokyo Service Center in Los Angeles; Margaret Endo and Sharon Kato Palmer of Keiro Services in Los Angeles; Josephine E. Yelder of Pepperdine University; Carnella J. Barnes of the Watts Health Foundation, Inc. in Lynwood, California; Jean Daniels of California State University, Northridge; Monica Hampton of People Coordinated Services of Southern California in Los Angeles; Marguerite V. Hodge of the American Lung Association in Los Angeles; Maria P. Cordero-Aranda of Calmecac Educational Services in Los Angeles; Lourdis Birba of American Health Geriatric Systems in Los Angeles, Maria Elena Gomez and I. Maribel Taussig of the University of Southern California in Los Angeles.

4. To learn about the information and referral procedures of Alzheimer's Association chapters and the capacity of Alzheimer's Association chapters to function as the basis of a national linking system for people with dementia, OTA contracted for a survey of 10 chapters. Nancy L. Mace conducted the survey. A questionnaire was developed and mailed to 10 chapters. The chapters were selected to reflect diversity in size, in services provided, in composition of staff (i.e., urban, suburban, or rural), and in other characteristics. The 10 chapters surveyed by OTA's contractor were:

- the Palm Beach County Chapter,
- the Detroit Area Chapter,
- the New York City Chapter,
- the Honolulu Chapter,
- the Albuquerque Chapter,
- the Central Virginia-Lynchburg Chapter,
- the Eastern Massachusetts Chapter,
- the Western North Carolina Chapter,
- the North Central Montana Chapter, and
- the Greater Kansas City Chapter.

OTA's contractor interviewed each chapter's president or executive director by telephone to obtain answers to the questions.

The findings of the survey are discussed primarily in the section on Alzheimer's Association chapters in chapter 8. A full report on the study, "The Role of ADRDA Chapters in Providing Information and Referral Services for Persons With Dementia" is available from the National Technical Information Service, #PB 90-123209.

In addition to these four small, exploratory studies, OTA contracted with Lisa P. Gwyther of Duke University for an analysis of factors that interfere with the use of services by people with dementia and their caregivers. The contract report, "Barriers to the Appropriate Use of Community-based Services by Families of Persons with Dementia," draws on the findings of several Duke University studies of people with dementia and their families but particularly the Duke University Respite Care Demonstration Project conducted from 1985-1987 in four counties in North Carolina. The conclusions of the contract report are discussed primarily in chapter 3. The full report is available from the National Technical Information Service, #PB 89-225205.

Appendix B

Acknowledgments

OTA is grateful for the assistance of the members of the Advisory Panel, contractors, and the many other individuals and organizations that contributed to this assessment. In addition to the members of the Advisory Panel, OTA acknowledges the following individuals for reviewing drafts of parts of this report.

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Appendix C

Reports by State Alzheimer's Disease Task Forces and Advisory Committees

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Several States have published State task force or advisory committee reports that specifically address Alzheimer's disease. Those reports are listed below. The list does not include State task force or committee reports on long-term care that may include Alzheimer-related issues.

Arizona

Arizona Advisory Committee on Alzheimer's Disease and Related Disorders, *Final Report of the Arizona Advisory Committee on Alzheimer's Disease and Related Disorders* (Phoenix, AZ: Arizona Department of Economic Security, Aging and Adult Administration, Oct. 1, 1989).

California

California Alzheimer's Disease Task Force, *The California Alzheimer's Disease Task Force—Final Report* (Sacramento, CA: 1987).

California Alzheimer's Disease Task Force, *The California Alzheimer's Disease Task Force Report on Insurance Coverage for Respite and Related Care* (Sacramento, CA: 1987).

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Appendix D

Glossary of Acronyms and Terms

Acronyms

AAA —area agency on aging
AAHA —American Association of Homes for the Aging
AARP —American Association of Retired Persons
ADEAR —Alzheimer's Disease Education and Referral (Center)
ADLs —activities of daily living
ADRCs —Alzheimer's Disease Research Centers
ADRDA —Alzheimer's Disease and Related Disorders Association
AIDS —acquired immunodeficiency syndrome
CASA —Community Alternative Systems Agency program (New York State)
CCCI —Connecticut Community Care, Inc.
CCP —Community Care Program (Illinois)
CDS —Consumer-Directed Services Initiative
CHC —community health center
CMHC —community mental health center
CSE —Community Services for the Elderly (New York State)
ECA —Epidemiologic Catchment Area (Survey)
EISEP —Expanded In-Home Services for the Elderly (New York State)
FHHC —Foundation for Hospice and Home Care
FSP —Family Survival Project (California)
GEU —Geriatric Evaluation Unit
GRECC —Geriatric Research, Education, and Clinical Center
HMO —health maintenance organization
HRSA —Health Resources and Services Administration
IADL —instrumental activities of daily living
IHSS —In-Home Supportive Services (program) (California)
JCAHO —Joint Commission on the Accreditation of Healthcare Organizations
LAMP —Long-Term Care Assessment and Management Program (Pennsylvania)
MSSP —Multipurpose Senior Services Program (California)
NLN —National League for Nursing
OTA —Office of Technology Assessment, U.S. Congress
PASSPORT—Pre-Admission Screening System Providing Options and Resources Today (Ohio)
PRO —peer review organization
SCAN —Senior Care Action Network (California)
SEED —Service Enriched Communities for the Elderly and Disabled (program) (California)
S/HMO —social health maintenance organization
SSI —Supplemental Security Income
TEFRA —Tax Equity and Fiscal Responsibility Act of 1982
VA —Veterans Administration
VHS&RA —Veterans Health Services and Research Administration
VNA —Visiting Nurse Association

Terms

Activities of daily living (ADLs): Activities related to personal care including bathing, dressing, getting in and out of bed or a chair, dressing, using the toilet, and eating. Compare *instrumental activities of daily living*.

Acute illness: An illness characterized by a single episode of fairly short duration, usually less than 30 days, and from which the patient can be expected to his or her normal or previous state of activity. Examples include infections such as pneumonia and influenza. Compare *chronic illness*.

Administration on Aging: The Federal agency within the U.S. Department of Health and Human Services that was established under the Older Americans Act of 1965 to administer the provisions of the act at the Federal level.

Adult day care centers: See *adult day centers*.

Adult day centers: Community-based entities that provide health care, social, and other services for small groups of functionally impaired adults in group setting during specified hours of the week. Some adult day centers are freestanding, and others are situated in hospitals, nursing homes, senior centers, or other agencies.

Aging network agencies: Agencies that are part of a loosely related network of agencies that have developed to serve elderly people since the enactment of the Older Americans Act in 1965. These agencies include the 57 State units on aging, the 670 area agencies on aging (AAAs), and thousands of other agencies that provide services for elderly people through contracts or other agreements with AAAs.

AIDS (acquired immunodeficiency syndrome): A disease caused by the retrovirus HTLV-III (human T-cell lymphotropic virus, type III) and characterized by a deficiency of the immune system.

AIDS dementia: A form of dementia that is due to brain infection by the virus that causes AIDS. The majority of people who have AIDS develop dementia. The special problems people with AIDS dementia confront in locating and arranging services are an important topic that is beyond the scope of this OTA report.

Alzheimer's Association: A national, privately funded, voluntary association, founded in 1980, to: 1) support research on Alzheimer's disease and related disorders; 2) stimulate awareness of Alzheimer's disease among the public and professionals; 3) encourage the formation of local chapters to create a nationwide family support network; 4) advocate legislation at the Federal, State, and local levels; and 5) provide services for patients and their caregivers. The Alzheimer's Association is also known as the Alzheimer's Disease and Related Disorders Association (ADRDA).

Alzheimer's Association chapters: Local chapters of the Alzheimer's Association. As of May 1990, there were 210 Alzheimer's Association chapters in 49 States (every State except Alaska).

Alzheimer's diagnostic and assessment centers: See *States' regional Alzheimer's diagnostic and assessment centers.*

Alzheimer's disease: A chronic, progressive disease of unknown cause that attacks brain cells or tissues and was first described by 1906 by German neurologist Alois Alzheimer. Alzheimer's disease is the most common cause of dementia in older people, accounting for 60 to 80 percent or more of all cases. A diagnosis of *definite* Alzheimer's disease requires histopathologic confirmation after the patient's death. A diagnosis of *probable* Alzheimer's disease can be made with confidence if there is a typical insidious onset of dementia with progression and if there are no other systemic or brain diseases—e.g., Parkinson's disease, multi-infarct dementia, drug intoxication, brain disease and other chronic infections of the nervous system, subdural hematoma, Huntington's disease, Creutzfeldt-Jacob disease, or brain tumor—that could account for the progressive memory and other cognitive deficits.

Alzheimer's Disease and Related Disorders Association (ADRDA): See *Alzheimer's Association.*

Alzheimer's Disease Research Centers (ADRCs): Fifteen centers, funded by the National Institute on Aging, that conduct biomedical and clinical research on Alzheimer's disease and provide educational programs for the public and information and referrals for people who are involved in their clinical research programs.

Appropriateness of a service: In the context of this report, those aspects of the service that make it consistent with the needs of a person with dementia.

Area agencies on aging (AAAs): Local public or private nonprofit agencies designated by States to implement certain provisions of the Older Americans Act. As of 1989, there were 670 AAAs. In general, AAAs are mandated to plan for and ensure the availability of services for elderly people rather than to provide the services directly. Some AAAs provide public education, information and referral, outreach, and case management for elderly people, including some people with dementia.

Assessment: An evaluation of an individual that usually includes the individual's physical, mental, emotional, financial, and social status. One objective of an assessment is to identify the kinds of services the individual needs.

Assessment instrument: A test or scale used to measure and evaluate an individual's status in various domains (e.g., physical, mental, emotional, financial, and social).

Autonomy: The quality or state of being self-governing or directing.

Behavioral problems: Behaviors of some individuals with dementia that are troublesome to the individual's family, other informal caregivers, and/or paid service providers (e.g., wandering, agitation, withdrawal, severe emotional outbursts, and disruptiveness at night).

Benefits counseling: Informing clients about sources of services and funding for services and how and where to apply for them.

Board and care facilities: Residential care facilities that provide room and board and variable amounts of protective supervision, personal care, and other services but not nursing care. Board and care facilities include adult foster care homes that provide care for one or two individuals as well as group homes, homes for the aged, and large domiciliary care facilities that may house several hundred people.

Capitation (or per capita) payment: A method of payment for services in which a service provider (e.g., a physician, hospital, or other agency or individual) is paid a fixed amount for each person served regardless of the actual cost of services provided for the person.

Care coordination: A term used by some people to refer generally to the functions OTA includes in its definition of case management.

Care management: A term used by some people to refer generally to the functions OTA includes in its definition of case management.

Caregiver: As used in this report, a relative, friend, neighbor, or other individual who provides care for a physically or mentally impaired person *on an unpaid basis.* A *primary caregiver* is the individual who provides most of the person's care; a *secondary caregiver* is an individual who helps out occasionally. The caregivers of people with dementia are usually their adult children and spouses, most of whom are women.

Caregiver support group: A group of people—including family members, friends, and others—who meet on a regular basis to share information, exchange coping strategies, and give and receive mutual support in caring for another person. Many support groups for caregivers of people with dementia are sponsored by Alzheimer's Association chapters. Other support groups for caregivers of people with dementia are sponsored by hospitals, other public and private agencies, and individual health care and social service professionals and service providers.

Case management: 1) A term used in a wide range of contexts in which its general meaning is the arrangement and coordination of services provided for an individual. The precise meaning of the term is often unclear. 2) As defined in this report, case management is a process that includes the following five functions:

- assessing a client's needs,
- developing a plan of care for the client,
- arranging and coordinating services for the client,
- monitoring and evaluating the services the client receives, and
- reassessing the client's situation as the need arises.

Case management—along with public education, information and referral, and outreach—is identified in this OTA report as one of the components of an effective system to link people with dementia to services.

Case manager: An individual who performs the five functions just listed. Nurses, social workers, and individuals with a college, but not a professional degree in a human service field frequently act as case managers for people with dementia, but individuals with other backgrounds and training also perform case management functions for some people with dementia.

Chore services: Services such as heavy house cleaning, minor household repairs, and yard work.

Chronic illness: An illness that lasts over an extended period of time and from which a person is not expected to recover. Examples are Alzheimer's disease, osteoarthritis, and diabetes. Compare *acute illness*.

Coexisting medical conditions: As used in this report, medical illnesses and conditions in a person with dementia that are unrelated or only peripherally related to the person's dementing disease.

Cognitive deficit/impairment: The loss of or a disturbance in one or more cognitive abilities, such as memory, intelligence, learning ability, problem-solving, judgment, comprehension, attention, and orientation to time and place and to oneself. Impairment of these abilities is a central feature of dementia.

Community health centers (CHCs): Organizations that provide primary health care and other health-related services to individuals in a local community. As of 1989, there were about 1,200 CHCs providing services at more than 2,000 sites throughout the country. Roughly half of these CHCs were receiving Federal grants under Section 330 of the Public Health Service Act, which authorizes grants to public and private nonprofit organizations that provide primary health care to populations or areas that are "medically underserved."

Community mental health centers (CMHCs): Local organizations that provide mental health services for people of all ages who have mental and emotional problems. There is no generally accepted figure for the number of CMHCs in the United States, in part because of lack of agreement about which agencies should be counted as CMHCs, but available data indicate that there are probably at least 2,300 CMHCs nationwide. Some CMHCs receive funding through the Federal Alcohol, Drug Abuse, and Mental Health Services Block Grant.

Companion services: Supervision, socialization, and other services such as reading, letter writing, and light errands, provided by an individual who comes to the home, often in the absence of the primary caregiver.

Competent/competency: As used in this report, terms that refer to the legal status of an adult who has not been declared incompetent by a court. Under U.S. common law, competent individuals have the right to control their property, manage their personal affairs, and give or withhold consent for medical treatment.

Congregate meals: Meals provided to a group of older adults in a community setting, such as a senior center or school.

Consolidated service system: See *service system*.

Counseling: Assistance and guidance provided by social workers, psychologists, nurses, and others to help define and resolve problems of various kinds, including, in the context of this OTA report, emotional and relationship problems related to the care of a person with dementia.

Decisionally capable/incapable: As used in this report, terms that refer to a person's ability/lack of ability to make decisions in a general sense rather than a legal one. If a person with dementia is decisionally incapable, decisions about services must be made for him or her. Compare *competent* and *incompetent*.

Decisionmaking capacity: As used in this report, a term that refers to the ability of a person to make decisions for himself or herself. Three types of criteria are generally used to judge an individual's decisionmaking capacity: *status criteria* (e.g., consciousness or age), *outcome criteria* (e.g., a judgment about the "reasonableness" of a person's decision), and *functional criteria* (e.g., evidencing an understanding of relevant information and issues).

Decision-specific decisionmaking capacity: An individual's capacity to make a specific decision. A concept that has emerged in the legal and ethical debate about determining individuals' decisionmaking capacity is that an individual's capacity to make a decision may differ for each decision, depending on the characteristics of the decision and the circumstances in which it must be made.

Dementia: A clinical syndrome characterized by a decline in mental function of long duration (months to years) in an alert individual. Symptoms of dementia include memory loss and the loss or diminution of other cognitive abilities, such as learning ability, judgment, comprehension, attention, and orientation to time and place and to oneself. Self-care and language abilities are usually also affected. Dementia can be caused by over 70 diseases and conditions, but the leading cause in older people is Alzheimer's disease.

Dementia-capable: As used in this report to characterize a system for linking people with dementia to services, a term that means being skilled in working with people with dementia and their caregivers, knowledgeable about the kinds of services that may help them, and aware of which agencies and individuals provide such services in a community.

Dementia-friendly: As used in this report to characterize a system for linking people with dementia to services, a term that means being responsive to people with dementia and their caregivers.

Dementia-specific: As used in this report to characterize a system for linking people with dementia to services, a term that means serving people with dementia exclusively.

Dementing illness, disease, or condition: One of the more than 70 illnesses, diseases, and conditions that can cause dementia. Dementing illnesses, diseases, and conditions are divisible into two groups: those in which the illness, disease, or condition inevitably produces dementia if it progresses through its full course, such as Alzheimer's disease, and those that may or may not produce dementia, such as certain infectious, metabolic, and nutritional disorders.

Domiciliary care facility: A nonmedical residential care facility that provides room and board and variable amounts of protective supervision, personal care, and other services. The term is used for the 29 large residential care facilities currently operated by the VA.

Durable power of attorney: A modification of the standard power of attorney that permits an individual (the principal) to transfer specified powers to another person. The power may be broad in scope or limited. The fundamental difference between standard and durable power of attorney is that the former loses its validity when the principal becomes incompetent and is therefore not useful for people with a dementing illness. A durable power of attorney provides a means of designating a surrogate decisionmaker that survives the incompetence of the principal.

Elderly: Generally referring to individuals over age 65.

Escort service: A service in which someone accompanies an individual to a medical appointment, another appointment, or an errand to provide assistance and supervision.

Ethics committee: A multidisciplinary group established in a hospital or nursing home to address ethical dilemmas that arise within the facility and advise the staff, patients (or residents), and their caregivers about difficult treatment decisions.

Ethnic minority group: A subgroup of the population that is characterized by a common language, culture, and historical background. According to this definition, everyone belongs to an ethnic minority group. In general, this report uses the term to refer to subgroups of four large minority groups (i.e., blacks, Hispanics, Asian Americans, and Native Americans.

Family caregiver: See *caregiver*.

Family consent laws: State statutes that authorize family members to make specified types of decisions (e.g., about life-sustaining medical treatments) for relatives who are decisionally incapable. Such statutes exist in a only a few States.

Family support group: See *caregiver support group*.

Family Survival Project (FSP): An organization in San Francisco that provides public education, information and referral, care coordination, and a variety of other services for brain-impaired adults and their caregivers. Under contract with the State of California. FSP serves as: 1) as the Bay Area Regional Resource Center for a six-county area; and 2) as California's Statewide Resource Consultant, which helps coordinate California's network of 11 regional resource centers for the caregivers of brain-impaired adults. The majority of FSP's clients have dementia.

Fee-for-service payment: A method of paying for services in which each service performed by an individual provider bears a related charge. This charge is paid by the individual patient receiving the service or by an insurer on behalf of the patient.

Financial/benefits counseling: See *benefits counseling*.

Functional impairment: A deficit in an individual's ability to function independently. Functional impairments in elderly people are often described in terms of deficits in *activities of daily living (ADLs)* and *instrumental activities of daily living (IADLs)*.

Gatekeeper: As used in this report, a term that refers to an individual, such as a mail carrier or utility meter reader, who interacts with many people in the course of his or her regular activities and has been specially trained to identify isolated elderly people who may be in need of assistance. (Note: To avoid confusion, this report does not use the term gatekeeper in another sense in which it is often used—namely to refer to an individual who allocates and controls the use of resources for an agency that provides health care, long-term care, social, or other services.)

Gatekeeper program: A type of outreach program used to identify isolated elderly people who may be in need of assistance. A gatekeeper program recruits and trains individuals who interact with many people in the course of their regular activities—e.g., mail carriers, utility meter readers—to identify isolated elderly people who may be in need of assistance and notify a central agency. The central agency then contacts the people, evaluates their needs, and refers them to services. Gatekeeper programs frequently identify isolated people with dementia who need assistance but would not contact a health care, long-term care, or social service agency for themselves.

Geriatric Research, Education, and Clinical Centers (GRECCs): Centers established at VA medical centers to provide basic and clinical research and education and training for clinicians and researchers in the field of geriatrics. As of 1990, there were 12 GRECCs, at least 4 of which were caring for some veterans with dementia.

Guardian: A person lawfully invested with the power and charged with the duty of protecting and taking care of the property and/or person of an individual who has been judged legally incompetent. In some States, the term used instead of, or in addition to, guardian is conservator.

Guardianship: A legal mechanism that involves the appointment by a court of an individual or institution (the guardian) to protect and take care of the person and/or property of a person who is found incapable of managing his or her own affairs (the ward). In some States, the term used instead of, or in addition to, guardianship is conservatorship.

Health care and social service professionals: Physicians, nurses, social workers, psychologists, physical therapists, speech therapists, occupational therapists, and other professionals who provide health care, health-related, and social services.

Health maintenance organization (HMO): An organization that provides directly or arranges for the provision of specified health care services to a voluntarily enrolled population for a fixed per capita payment rather than a fee for each services. Typically, a physician, a nurse, or another individual is in charge of each enrollee's care and is responsible for authorizing and arranging any special services for the person.

Home care agency: See *home health agency*. Both terms are used synonymously in this report.

Home care services: Health care, long-term care, social, and other services provided in the home by a home health agency or other organization or individual. Home care services range from nonmedical services (e.g., paid companion and housekeeping services) to health care and health-related services (e.g., skilled nursing and physical therapy).

Home-delivered meals: Meals prepared at a central location and delivered to homebound people on a daily or less frequent basis.

Home health agency: A local organization that provides in-home services. As used in this report, the term includes agencies that provide skilled nursing care, physical therapy, and other health care and health-related services, as well as homemaker and other agencies that provide social and other nonmedical in-home services. In 1989, there were about 12,800 home health agencies in the United States, including about 5,700 agencies that were certified to provide Medicare-covered home health care and about 7,100 other agencies that provided in-home services but were not Medicare-certified. To be certified by Medicare, a home health agency must provide skilled nursing care and meet certain other requirements.

Home health aide: A person who is paid to provide health-related services in the home. The services provided by a home health aide may include assistance with medications and exercise, assistance with personal care (e.g., bathing, dressing, and feeding), and light household tasks. The term is sometimes used synonymously with the term homemaker, but some agencies and others make a distinction between the two terms.

Home health care agency: See *home health agency*.

Homemaker: A person who is paid to provide in-home services, such as assistance with personal care (e.g., bathing, dressing, and feeding), household tasks, meal preparation, and shopping. The term is sometimes used synonymously with the term home health aide, but some agencies and others make a distinction between the two terms.

Hospice services: Medical, nursing, counseling, and other supportive services rendered to terminally ill people and their families. Hospice care is intended to be palliative and to improve quality of life rather than to cure disease or extend life.

Hospital-based geriatric assessment programs: Special hospital inpatient or outpatient programs that use a multidisciplinary team to evaluate elderly patients with complicated medical or psychiatric problems and to develop a coordinated plan of care. Some hospital-based geriatric assessment programs also offer other services such as medical and psychiatric treatment, and rehabilitative services. Hospital-based geriatric assessment programs include inpatient geriatric specialty units, inpatient geriatric consultation services, outpatient geriatric services, and inpatient and outpatient geropsychiatry services. As of 1987, about 1,400 hospitals nationwide had a geriatric assessment program.

Hospital discharge planner: A person who arranges post-discharge care for hospitalized patients.

Huntington's disease: A genetic disease characterized by chronic progressive disorders of movement and mental deterioration culminating in dementia. Symptoms do not usually appear until late middle age, and death usually results within 15 years.

Incompetent: As used in this report, a term that refers to the legal status of a person who, on the basis of evidence presented to a court, has been declared incapable of managing his or her affairs. Compare *decisionally capable/incapable*.

Informal caregivers: See *caregivers*.

Informal services: As used in this report, unpaid services provided for an impaired person by his or her relatives, friends, neighbors, or others.

Information and referral: As defined in this report, information and referral means providing information about and referrals to specific services and sources of funding for services in a community. Information and referral—along with public education, outreach, and case management—is identified in this OTA report as one of the essential components of an effective system to link people with dementia to services.

In-home services: Health care, long-term care, social, and other services provided in the home by a home health agency or other organization or individual. In this report, the term is used synonymously with the term *home care services*.

Instrumental activities of daily living (IADLs): Activities related to independent living, such as preparing meals, doing laundry, managing money, shopping for groceries, cleaning the house, cooking, using a telephone, and taking medications. Compare *activities of daily living*.

LAMP (Long-Term Care Assessment and Management Program): A program in Pennsylvania that contracts with local agencies (usually area agencies on aging) to provide case management for elderly people who are eligible for Medicaid-funded nursing home care but choose to remain at home. It is similar to Ohio's PASSPORT Program but is paid for solely with State funds.

Legal services: Assistance with legal matters, such as property disposition, transfer of assets, wills, living wills, powers of attorney, and guardianship.

Life-sustaining medical treatments: Drugs, medical devices, or procedures that can keep a person alive who would otherwise die within a foreseeable, though usually uncertain, time. Examples include cardiopulmonary resuscitation, mechanical ventilation, renal dialysis, and nutritional support (i.e., tube or intravenous feeding).

Linking program: As used in this report, a program that provides one or more of the functions identified by OTA as essential components of an effective system to link people with dementia to services (i.e., public education, information and referral, outreach, and case management).

Living will: A legal mechanism, recognized in some States, that permits a competent individual to declare his or her wishes, especially the intent to refuse life-sustaining procedures once he or she is incompetent and death is imminent. Along with durable powers of attorney, living wills are legal mechanisms that give individuals the ability to direct treatment decisions after incompetence.

Long-distance caregiver: An adult child or other relative or friend of an impaired person who lives in a different locality or area of the country but still tries to function as a caregiver for the person—often by trying to locate, arrange, and monitor services for the person. The difficulties long-distance caregivers face in locating and arranging appropriate services for a relative or friend with dementia are one of the primary reasons that a system to link people with dementia to services must be uniform in some way nationally.

Long-term care services: A variety of services that may be provided in a person's home, the community, or a residential or institutional setting, with the objective of maintaining and supporting a chronically ill or severely disabled individual. The services generally are needed for a prolonged period, even if intermittently.

Medicaid: A joint Federal/State program intended to provide health care and health-related services for low-income individuals. Medicaid regulations are established by each State within Federal guidelines, and the eligibility requirements and services covered vary significantly among the States. In general, Medicaid pays for medical, nursing home, and home health care for individuals who meet the eligibility requirements for those services. In some States, Medicaid also pays for adult day care and in-home services such as personal care and homemaker services. Financial eligibility for Medicaid is determined by a means test, in which a ceiling is placed on the maximum income and assets an individual may have in order to qualify for assistance. The income and assets levels are low in all States and very low in some States.

Medicaid 2176 Home and Community-Based waiver: A waiver obtained under the Medicaid 2176 Home and Community-Based Waiver program which allows States to provide a coordinated package of home and community-based services for individuals who otherwise would be at risk of nursing home placement or who are already in an institution. A State with a Medicaid 2176 waiver may use Medicaid funds to pay for services that are not ordinarily covered by Medicaid; may pay for services for some Medicaid beneficiaries and not others, so that benefits can be targeted; and may use a higher income standard to determine eligibility for the waiver program than the standard used for other Medicaid services. Although States' Medicaid 2176 waiver programs are a valuable resource in linking some people with dementia to services, many people with dementia are not eligible for the programs because they do not have medical conditions, functional impairments, or financial resources that meet the eligibility requirements for Medicaid-funded nursing home care.

"Medically needy" people: Under Medicaid, people whose incomes are above the ceiling established by a State for Medicaid eligibility but who qualify for Medicaid, nevertheless, because their medical expenses reduce their incomes below the Medicaid eligibility level. Not all States allow Medicaid eligibility for "medically needy" people.

Medicare: A nationwide health insurance program authorized in 1965 to pay for hospitalization, medical care, and some related services for people over age 65, people who have received Social Security disability insurance payments for 2 years or longer, and people with end-stage renal disease. Medicare consists of two programs: hospital insurance (Part A) and supplementary medical insurance (Part B).

Medicare Alzheimer's Disease Demonstration: A demonstration program, mandated by Congress in 1986, to determine the effectiveness, cost, and impact of providing comprehensive services for Medicare enrollees who have Alzheimer's disease or a related disorder. As of 1990, the demonstration is being implemented at eight sites nationally.

Minority group: See *ethnic minority group.*

Multidimensional assessment: A client evaluation that focuses on many different aspects of the client's status, e.g., physical, mental, emotional, functional, financial, and social.

Multidisciplinary assessment: A client evaluation conducted by individuals from various disciplines, usually including a physician, a nurse, and a social worker and, depending on the care setting, a physical therapist, a speech therapist, an occupational therapist, a psychologist, and various physician specialists.

Multidisciplinary team: A team composed of individuals from various disciplines that provides comprehensive client assessments, care planning, and/or treatment. Multidisciplinary teams usually include a physician, a nurse, and a social worker and, depending on the care setting, may also include a physical therapist, a speech therapist, an occupational therapist, a psychologist, and various physician specialists.

Multi-infarct dementia: An irreversible form of dementia resulting from many small strokes. This is the second most common cause of dementia in the elderly.

Nursing homes: Residential care facilities that provide 24-hour supervision, nursing care, personal care, and other services. An estimated 40 to 70 percent of nursing home residents have dementia, and many people with dementia spend some time in a nursing home in the course of their illness. Medicaid pays for a significant proportion of nursing home care, but nationally half the cost of nursing home care is borne by residents and their families.

Nursing home preadmission screening programs: Programs to evaluate nursing home applicants and divert those who can be cared for at home. As of 1986, 29 States and the District of Columbia has nursing home preadmission screening programs. In 1987, a Federal law as enacted that requires States to establish a nursing home preadmission screening program to identify mentally ill and mentally retarded people for whom nursing home placement is inappropriate.

Occupational therapy: Therapy provided to people who are physically or mentally impaired that is intended to improve functional abilities; provided by an occupational therapist.

Older Americans Act: A law enacted in 1965 that established the Federal Administration on Aging and a program of Federal grants to States for the development of a coordinated system of services for elderly people in their homes and communities. The act also required States to designate a single State agency—commonly referred to as a State unit on aging—to formulate a plan for developing the system of services envisioned in the act. The 1973 amendments to the act required each State to divide its jurisdiction into planning and service areas and to designate an area agency on aging to plan, coordinate, and arrange services for elderly people in each area.

On Lok Senior Health Services: An organization that plans, coordinates, and provides comprehensive health care, long-term care, social, and other services for about 300 very frail and severely impaired older adults in the Chinatown-North Beach area of San Francisco. On Lok's comprehensive, consolidated service program exemplifies a model of service delivery that eliminates for its clients the problems in locating and arranging services that are the focus of this OTA report.

Outcome criteria to measures quality of care: Criteria for measuring quality that focus on the outcome of care (e.g., the patient's health and functional abilities and patient and family satisfaction). The use of outcome criteria to measure quality assumes a direct link between the process of care and the outcomes of care. In the case of people with dementia, however, that link is seldom straightforward or clear since many factors other then quality of care influence patient outcomes. Compare *process criteria* and *structural criteria to measure quality of care.*

Outreach: As defined in this report, outreach means using an active method to identify individuals with dementia and caregivers who need assistance but are unlikely to respond to public education programs or to contact an information and referral source on their own. Outreach is likely to be needed for isolated people with dementia who live alone and have no relative or friend to help them and for people with dementia whose caregiver is isolated and overburdened. Outreach—along with public education, information and referral, and case management—is identified in this OTA report as one of the essential components of an effective system to link people with dementia to services.

Parkinson's disease: A disease affecting movement and leading to dementia in approximately one-third of those affected. The disease is associated with destruction of cells in the brain-stem. The symptoms of Parkinson's disease include tremors, rigidity, extreme slowness of movement, and a mask-like facial expression.

PASSPORT (Pre-Admission Screening System Providing Options and Resources Today): A Medicaid 2176 waiver program in Ohio that provides case management and a range of in-home and community services for people who are eligible for Medicaid-covered nursing home care but choose to remain at home, including some people with dementia.

People with dementia: As used in this report, the term refers to people with Alzheimer's disease, and other dementing diseases that primarily affect elderly people.

Personal care services: Assistance with self-care activities, including eating, dressing, bathing, getting in and out of bed, and using the toilet.

Personal emergency response system: A telephone-based system to alert others that an individual who is alone is experiencing an emergency and needs assistance.

Physical therapy: Rehabilitative therapy provided by a physical therapist. The therapy may include a variety of methods, such as heat, hydrotherapy, massage, exercise, and the use of mechanical devices.

Preadmission screening: See *nursing home preadmission screening programs.*

Prevalence: The total number of individuals in a given population who have a specific disorder at one period in time.

Primary caregiver: See *caregiver.*

Private geriatric case manager: Individual professionals (usually social workers or nurses) and others who provide client assessment, care planning, service arrangement and coordination, monitoring, and a variety of services for elderly people on a fee-for-service basis. Although no data are available, anecdotal evidence suggests that many clients of private geriatric case managers have dementia.

Process criteria to measure quality of care: Criteria for measuring quality that focus on the activities involved in providing care (e.g., care planning and medication procedures and procedures for handling difficult patient behaviors). The use of process criteria to measure quality is valid only if the processes have been linked to desired or undesired outcomes of care. Compare *outcome criteria* and *structural criteria to measure quality.*

Prospective payment: Payment for medical care on the basis of rates set in advance of the time period in which they apply. Medicare's DRG payment system for inpatient hospital services is a particular form of prospective payment.

Protective services: Social and law enforcement services to prevent, eliminate, or remedy the effects of physical and emotional abuse or neglect.

Public education: As defined in this report, public education means providing programs and materials to help people understand dementia and the kinds of services that may be helpful for individuals with dementia. Public education—along with information and referral, outreach, and case management—is identified in this OTA report as one of the essential components of an effective system to link people with dementia to services.

Quality assessment: The measurement and evaluation of quality of care.

Quality assurance: Procedures and activities to safeguard or improve quality by assessing quality and taking action to correct any problems found.

Quality of care: The extent to which the service increases the probability of desired outcomes and reduces the probability of undesired outcomes, given the constraints of existing knowledge.

Regional Alzheimer's diagnostic and assessment centers: See *States' regional Alzheimer's diagnostic and assessment centers.*

Regional resource centers: California's 11 regional centers that provide public education, information and referral, and care coordination, and a variety of other services for brain-impaired adults and their caregivers. The majority of the clients of California's regional resource centers are caregivers of people with dementia. One of the centers is the *Family Survival Project*, which is the model for the other 10 centers.

Residential care facility: A care setting in which the patient or client resides, such as a nursing home, board and care facility, or State mental hospitals.

Respite care services: Any short-term services that are intended to provide temporary relief for the primary caregiver of an impaired person. Such services may include in-home companion/sitter services, in-home personal care, adult day care, or short-term (e.g., overnight) stays in a nursing home.

Senior center: A community facility for elderly people. Senior centers provide various activities for elderly people, recreational, educational, cultural, or social events. Some centers provide adult day care, congregate meals, health screening, and limited health care services.

Service consciousness: As used in this report, a general awareness that services exist. Service consciousness is one of two components of patients' and caregivers' knowledge about services. Compare *service knowledge.*

Service knowledge: Knowledge about a specific service, including who provides it in a community. Service knowledge is one of two components of patients' and caregivers' knowledge about services. Compare *service consciousness.*

Services for people with dementia: In the context of this report, services for people with dementia means all health care, long-term care, social, and other services that may be needed by a person with dementia. Such services include diagnosis, acute medical care, adult day care, chore services, escort service, financial/benefits counseling, home-delivered meals, hospice, legal services, mental health services, multidimensional assessment; occupational therapy; personal care, homemaker services, physical therapy, recreation/exercise, respite care, skilled nursing, speech therapy, vision care, and other services. In this report, the term "services" is not used for the four linking functions—public education, information and referral, outreach, and case management.

Service system: As used in this report, an organizational entity that pools funds from several sources and integrates the functions of various agencies that provide services in a given geographic area. These entities are intended to create a consolidated system through which people are connected to services.

Service-connected disabilities: With respect to the eligibility criteria for VA services, disabilities that were incurred or aggravated during military service. Veterans with a service-connected disability have priority for VA services.

Severely mentally ill: A term that usually refers to adults with a diagnosis of schizophrenia, a major affective disorder, psychosis, or a personality disorder and a recent history of psychiatric care that required more than voluntary outpatient treatment. The term is not usually used to refer to people with Alzheimer's disease or other diseases that cause dementia.

Social health maintenance organization (S/HMO): An innovative organizational entity that offers voluntarily enrolled elderly Medicare beneficiaries a package of acute and long-term care services and operates on a capitated, prospectively fixed budget. As of 1990, there were four S/HMOs in this country, all of which were part of a congressionally mandated demonstration project—the National S/HMO Demonstration.

Social Services Block Grant: A Federal block grant to States for social services for elderly and disabled people and others. There are no Federal requirements for specific services that must be provided, but many States use a portion of their Social Services Block Grant funds for board and care, adult day care, home health aide, homemaker, and chore services. States determine the eligibility requirements for these services and may use a means test.

Special care units: Units in nursing homes and board and care facilities that provide "special care" for people with dementia.

Speech therapy: Treatment to improve or restore speech; provided by a speech therapist.

State unit on aging: A State agency designated under the provisions of the Older Americans Act to formulate a plan for developing the system of community services envisioned by the act and to oversee the use of Older Americans Act funds in the State. Currently, there is a State unit on aging in each of the 50 States, the District of Columbia, and 7 territories.

States' regional Alzheimer's diagnostic and assessment centers: A general name used in this report to refer to regional centers established by States to provide diagnosis, a comprehensive assessment, and a plan of care for people suspected of having Alzheimer's disease or a related disorder. Some States' regional Alzheimer's diagnostic and assessment centers also provide services, such as medical treatment, psychiatric treatment, adult day care, caregiver education and training, and caregiver support groups, and most centers assist in locating and arranging services for their clients. Many of the centers also conduct biomedical and clinical research. States with such centers include California, Connecticut, Florida, Illinois, Kentucky, Maryland, New Jersey, New York, Ohio, and Pennsylvania.

Structural criteria to measure quality: Criteria for measuring quality that focus on the resources available for care (e.g., the number and qualifications of staff, and an agency's physical plant, and financial resources). The use of structural criteria to measure quality is valid only if the specific structural characteristics measured are associated with better processes or outcomes of care. Compare *outcome criteria* and *process criteria to measure quality.*

Supervision: Monitoring of an individual's status and activities to ensure his or her safety.

Supplemental Security Income (SSI): A Federal income support program that provides a monthly payment for disabled, aged, and blind people with incomes below a specified level.

Support group: See *caregiver support group.*

Surrogate decision: A decision made on behalf of another person, in particular a person who is decisionally incapable. Court rulings and legal analysis of decisions about the use of life-sustaining technologies have identified two standards to guide surrogate decisionmaking: 1) the "best interest standard" (which requires the surrogate to make decisions from the perspective of hypothetical reasonable person, using objective, societally shared criteria); and 2) the "substituted judgment standard" (which requires the surrogate to make decisions from the perspective of the patient, using the patient's personal values and preferences).

Surrogate decisionmaker: A person who makes decisions about the health care, lifestyle, and estate of another individual who is incapable of making the decisions for himself or herself. A surrogate decisionmaker can be a court-appointed conservator or guardian, or a family member who makes decisions for an impaired relative without being formally or legally charged to do so.

Temporary treatment guardian: Volunteers used at the University of New Mexico's Institute of Public Law to ascertain the wishes and preferences of hospitalized elderly people who were too cognitively impaired to make decisions about their own care and had no relative or friend to make decisions for them.

Third-party payment: Payment by a private insurer or government program to a service provider for care given to a patient.

Validity: As used in this report, the extent to which the criteria used to measure the quality of services actually measure quality

Values history document: A document that expresses a person's wishes, values, and preferences with respect to his or her care. Such documents have been developed and tested at the University of New Mexico's Institute of Public Law.

Visiting nurse: A registered nurse who provides nursing care for an individual at home.

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